

**MENTAL HEALTH, MARITAL INTIMACY AND SUPPORT IN  
ELDERLY CAREGIVERS OF PHYSICALLY FRAIL PARTNERS**

**Ishbel Dumughn**

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This thesis has been composed by myself, and the work within it is my own.

Ishbel Dumughn

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## **ABSTRACT**

The impact of caregiving and the role of psychosocial resources are examined in elderly spouses of the physically frail. Despite evidence from the literature, the strain of caring for older people with physical illnesses is less well recognised than that of caring for dementia sufferers. Similarly, although marriage is the prime location of care, the impact on the marital relationship is little studied. In this study elderly spouse caregivers were interviewed before and after their partner's attendance at a day hospital. Questionnaires were used to assess stressors, mood, general mental health and perceptions of strain, marital intimacy and social support. It was predicted that these caregivers would experience significantly poorer mental health than the general population, with low levels of marital intimacy and social support. The relationship between these variables was therefore explored using a longitudinal design. It was predicted that mental health would be significantly improved at the second meeting, principally predicted by the caregiver's satisfaction with the formal service and their perceptions of informal support and intimacy. Gender differences were explored and qualitative data presented. The results are discussed with reference to the implications for formal service provision and methodological issues are highlighted.



# CONTENTS

<b>1</b>	<b>Introduction</b>	<b>1</b>
<b>1.1</b>	<b>The Impact of Caregiving</b>	<b>3</b>
1.1.1	Mental Health	3
	<i>Is there an impact?</i>	3
	<i>What models can be used to understand caregiver stress?</i>	4
	<i>Does the type and severity of illness affect caregiver strain?</i>	6
1.1.2	Social Relationships	8
1.1.3	The Marital Relationship	9
	<i>What is the impact on the marital relationship?</i>	10
	<i>What factors mediate the impact on the marital relationship?</i>	11
<b>1.2</b>	<b>The Role of Psychosocial Resources</b>	<b>13</b>
1.2.1	Social Relationships and Informal Support	15
	<i>By what mechanism does social support affect mood?</i>	15
	<i>Social support and elderly spouse caregivers</i>	17
1.2.2	Formal Services	18
<b>1.3</b>	<b>Gender</b>	<b>20</b>
1.3.1	The Politics of Gender in Caregiving	20
1.3.2	Gender Differences in the Experience of Burden	22
	<i>Gender roles, coping and differences in social relationships</i>	23
<b>1.4</b>	<b>Methodological Issues</b>	<b>25</b>
<b>1.5</b>	<b>Aims</b>	<b>26</b>
<b>1.6</b>	<b>Hypotheses</b>	<b>26</b>

<b>2</b>	<b>Method</b>	
2.1	Design	28
2.2	Participants	28
2.2.1	Recruitment	28
2.2.2	Sample Size	29
2.2.3	Sample Characteristics	30
2.3	Measures	31
2.3.1	Mental Health and Experience of Strain	31
2.3.2	Subjective Stressors	32
2.3.3	Objective Stressors	33
2.3.4	Social Support and Marital Intimacy	34
2.4	Procedure	35
2.4.1	Interview One	35
2.4.2	Interview Two	36
2.4.3	Interview Three	37
2.5	Analysis of Data	37
2.5.1	Coding Data from the Interview	37
2.5.2	Levels of Significance	38
2.5.3	Normality of the Data	38
<b>3</b>	<b>Results</b>	<b>39</b>
3.1	Comparing the Recruited Group with Non-Attendees	39

<b>3.2 Hypothesis One - The Impact of Caregiving</b>	<b>39</b>
3.2.1 Mental Health	40
3.2.2 Marital Intimacy	41
3.2.3 Social Support	42
3.2.4 Subjective Stressors and Objective Burden	44
3.2.5 Mental Health and Objective and Subjective Burden	45
 <b>3.3 Hypothesis Two - The Relationship between Mental Health and Psychosocial Resources</b>	 <b>47</b>
3.3.1 The relationship between social support and mental health	47
3.3.2 The relationship between marital intimacy and mental health	51
3.3.3 The relationship between psychosocial resources and burden	52
3.3.4 Comparing the depressed and non-depressed subgroups	53
 <b>3.4 Hypothesis Three - Predictors of Change in Mental Health</b>	 <b>54</b>
3.4.1 A Description of Changes between time one and time two	54
3.4.2 Changes in Caregiver Mental Health	55
3.4.3 Change in Subjective Burden	57
3.4.4 Changes in Caregiver Mental Health (controlling for other changes)	57
3.4.5 Predictors of Change in Mental Health measures	59
3.4.6 Change in Mental Health at Time Three	65
 <b>3.5 Hypothesis Four - Gender Effects</b>	 <b>67</b>
3.5.1 Gender Differences in Demographics and Objective Burden	67
3.5.2 Gender Differences in Mental Health	67
3.5.3 Gender Differences in Marital Intimacy and Satisfaction	69
3.5.4 Gender Differences in Social Support	70

3.5.5	Gender Differences in the Relationship between Mental Health and Psychosocial Resources	71
3.5.6	Gender Differences in Subjective Burden	72
<b>3.6</b>	<b>Thematic Analysis of Qualitative Data</b>	<b>73</b>
3.6.1	The Impact of Caregiving	73
3.6.2	Coping	77
3.6.3	Why Do It?	78
3.6.4	Views on Formal Services and Informal Help	79
3.6.5	Views on the Day Hospital	81
3.6.6	Feelings about the Future	82
3.6.7	Gender Differences	84
<b>4</b>	<b>Discussion</b>	<b>86</b>
4.1	Summary of the Main Findings	86
4.2	Recruitment and Sample Characteristics	86
4.3	The Impact of Caregiving	88
4.3.1	Mental Health	88
4.3.2	Marital Intimacy	91
4.3.3	Social Relationships	93
4.3.4	Subjective Stressors and Objective Burden	94
4.4	The Relationship between Mental Health and Psychosocial Resources	96
4.4.1	Social Relationships	96
4.4.2	The Marital Relationship	97

<b>4.5 Predictors of Change in Mental Health</b>	<b>99</b>
4.5.1 Changes in Mental Health	99
4.5.2 Predicting Mental Health	101
4.5.3 The Effect of Day Hospital Attendance on Mental Health	102
 <b>4.6 Gender Differences</b>	 <b>103</b>
4.6.1 Gender Differences in Demographics and Objective Burden	103
4.6.2 Gender Differences in Mental Health and Burden	104
4.6.3 Gender Differences in Social Relationships	105
4.6.4 Gender Differences in the Marital Relationship	106
 <b>4.7 Methodological Issues</b>	 <b>107</b>
 <b>4.8 Conclusions and Avenues for Future Research</b>	 <b>109</b>

## References

## Appendices

Recruitment Letter
Geriatric Depression Screening Scale
General Health Questionnaire
Likert Scales
Pearlin's Subjective Stressors
Gilleard's Problem Checklist
Significant Other Scale – B
Marital Intimacy Questionnaire
Interview
Qualitative Data

# 1 INTRODUCTION

Informal caregiving is not a new phenomenon, but research into it has flourished over the last twenty years. This is in part due to the steadily increasing overall life expectancy in the Western world, which is not well matched with an increase in the span of healthy life a person can expect. There are therefore increasing numbers of physically and mentally frail older adults requiring care. With a National Health Services whose resources are already stretched, there is increasing pressure for this care to be provided by friends and relatives as 'informal care'. As is made explicit in the Department of Health and Social Security White Paper of 1981, care *in* the community must now mean care *by* the community. Informal caregivers are therefore a crucial resource with older adults being the principal source of informal care for older adults.

Caregiving is defined by different authors in different ways, and there is little in the way of consensus that may be used in research studies. For example Travers (1996) defines activities as informal caregiving only if they occupy over 20 hours per week. Others define caregiving in terms of help in a minimum number of activities of daily living (ADLs). Yet others define informal caregiving more loosely as the activities and experiences involved in providing help and assistance to someone (Pearlin, Mullan, Semple and Skaff, 1990). This latter definition includes both the experience of caring as an affective component of commitment to someone, as well as the behavioural expression of that commitment. This begins to highlight the important point that caregiving is embedded in normal relationships. There is a continuum of quantitative and qualitative changes within those relationships from caring about, to helping, to caregiving. These changes can engender stress within that relationship, and within the person providing the care. With increasing life expectancies, couples are having to cope longer with their illnesses (Rolland, 1994). It is important to understand this stress, both in terms of promoting the well-being of individuals and in terms of maintaining the resource of informal caregiving.

A wealth of research throughout the eighties served to establish that caregiving is indeed associated with increased rates of physical and psychiatric morbidity (Schultz et al, 1990). This is in part due to the direct effect of the burden of caregiving, but

there is also an indirect impact on the social relationships of the caregiver. This principally negative effect is mediated and moderated by certain factors, and study of caregiving has become a fertile ground for the study of stress mediation. Psychosocial resources such as support and individual coping strategies have particularly been studied. Given the adverse impact of caregiving on social relationships, it is paradoxical that one of the factors suggested to be related to lower levels of distress in the longer term is the presence of informal supporting relationships (Hansson & Carpenter, 1994). With the spouse being the principal source of support in most situations (Henderson, 1977), it can be seen that spouse caregivers may be particularly burdened. However the formal support of services such as day hospitals aim to relieve the caregiver's burden. Other mediating and moderating factors include the coping strategies adopted by the caregiver, and their perceptions and attributions about their situation. The background and gender of the person providing care also affects their experience of the caregiving situation and the help they receive.

It should be noted that this study concerns caregivers in Britain and that much of the research drawn on is also based within Western cultures. The status of older people and of those who care for them varies with culture. In the West there tends to be a negative stereotype and prejudice against the old. Caring for older people tends also to be similarly stigmatised, under-resourced and unsupported. In other cultures where age is more respected, caring for older relatives can be regarded as an honour.

This study aims to explore the impact of caregiving on psychological well-being and relationships in a situation where a physically frail spouse is the recipient of the care. Caregivers' gender, and their perceptions of their relationships and supports, will also be explored in order to understand how they might relate to levels of depression and stress. In this introduction I will review the research into the impact of caregiving, the role of support and issues of gender in caregiving in Western cultures.

## **1.1 The Impact of Caregiving**

### ***1.1.1 Mental Health***

Since Grad and Sainsbury's work with caregivers of dementia sufferers, it has been recognised that caring for a relative is stressful (Grad and Sainsbury, 1965). This is both in terms of the objective, physical burden of caregiving and in terms of the subjective, emotional impact on the caregiver. Other researchers since then have found similar results with other groups, particularly concentrating on psychological well being.

#### ***Is there an impact?***

Schultz et al (1990) provide a general review of studies exploring psychiatric and physical morbidity in caregivers. They note increased self-reports of psychiatric symptomatology and illness in most caregivers. Gilhooly (1994) reviews many of those studies concerning dementia sufferers and cites between 31% and 73% 'caseness' in carers in studies using the General Health Questionnaire (Goldberg and Hillier, 1979). Morris et al (1988b) also review studies of dementia sufferers and they conclude a range of 14% to 40% clinical depression. In addition, Schultz et al (1988) found that those providing care to stroke victims had rates of depression 2.5 to 3.5 times higher than controls. Coyne and Smith (1991) found that a third of wives looking after husbands following myocardial infarction reached psychiatric caseness on a symptom checklist. Kiecolt-Glaser et al (1995) found an indirect manifestation of psychological distress in terms of significantly slower wound healing in women looking after relatives with dementia. Caregiving can also have an indirect effect on physical health in that the carer may feel that she has no time to be ill, or to take time to recover (Parker, 1993). Forbes (1996) notes that up to a third of carers report loneliness. Interestingly in her own study Gilhooly (1984) found no significant levels of stress in caregivers of dementia sufferers; however she notes a possible 'survivor' effect whereby those caregivers most stressed probably give up their role and those remaining in the community are probably those who cope.



Many caregivers are elderly, with Travers (1996) suggesting that over a third of informal care to people over the age of 65 is provided by people over 70. Fisher (1994) therefore encourages society to see elderly people as a resource rather than a burden. It should be noted that it is no longer accepted that depression can be thought of as a 'normal' or inevitable part of the ageing process (Roberts, Kaplan, Shema and Strawbridge, 1997). Studies finding psychological morbidity in elderly carers are generally comparing them with age matched controls or appropriate norms in order to make clear the difference between elderly caregivers and other groups of older people. It may however be accepted that age is a vulnerability factor for depression in the caregiving situation. Rolland (1994) notes that elderly couples are more vulnerable to depression than younger ones when facing sickness within their relationship, and he explains this principally in terms of the lost plans for retirement. There are other vulnerabilities for depression found in a caregiving population, for example the population tends to be female, unemployed and of a lower socio-economic status. These factors will not necessarily be controlled for by the use of normative data from the general population. However Tennstedt et al (1992) found rates of depression higher than would be expected, even given these additional vulnerabilities within the population.

In summary there is a considerable body of evidence to suggest that rates of psychological morbidity are higher amongst caregivers than in the general population. This is particularly seen in elderly caregivers, and cannot be fully explained by other vulnerability factors such as age, gender and social class. The study of the well being of older caregivers seems particularly important for these reasons, and will be addressed in this study.

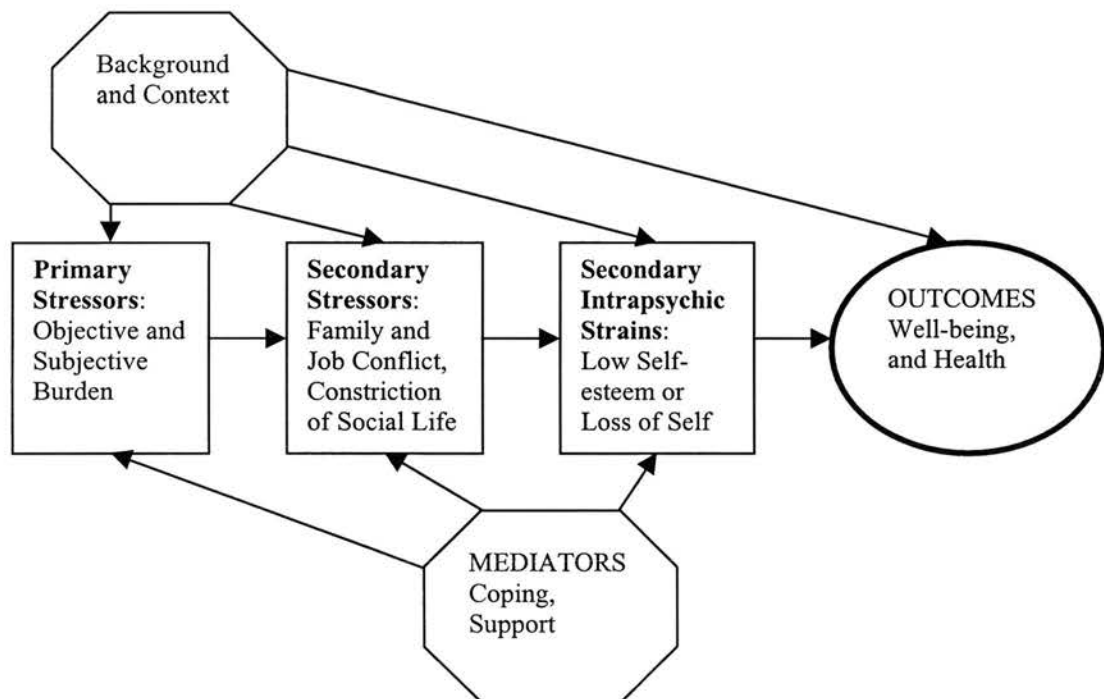
### ***What models can be used to understand caregiver stress?***

It can be seen from the variety of research quoted above that the study of caregiving is complex and multi-factorial, so that beyond the initial statement that the role is 'stressful' in some way there is less agreement between researchers. Zarit and Edwards (1996) ask that research take account of this complexity and the huge individual variation in caregiver's experiences, so that services may be planned appropriately. Gilhooly (1994) notes that the early generation of studies of caregivers

established the presence of stress, whilst more recent studies are rightly concentrating on ‘fine tuning’ this knowledge. The methodological difficulties of caregiver research will be addressed more fully in a later section, but here I will outline two models, which are helpful in conceptualising caregiver stress.

Henderson’s work on depression using an ethological approach provides a helpful way of understanding why people may experience distress (Henderson, 1974). He describes depression as a ‘care-eliciting syndrome’ with the sufferer perceiving him or herself as receiving inadequate care from others. He therefore uses pathological expressions of normal attachment behaviour, the symptoms of depression, in order to try to bring important others closer. The caregiver may receive inadequate care as he finds himself in an unbalanced or ‘one way’ relationship, and this neglect would then lead to care-eliciting symptoms. Attachment and the balance of exchange in relationships are especially important where it is the marital relationship that becomes the setting for caregiving.

In terms of understanding the processes of caregiver strain, Pearlin et al (1990) provide a useful and widely used model (see Figure 1.1.1).



**Figure 1.1.1; a model of caregiver stress (Pearlin et al, 1990).**

This model takes account of the inter-relatedness of the factors involved in caregiver stress. It also provides a framework for organised research into the questions of the context of caregiving, the stressors involved, the secondary effects and the factors that mediate against stress, and is well reviewed by Zarit and Edwards (1996). The model was used extensively by Aneshensel, Pearlin and colleagues in a longitudinal study of 555 caregivers over three years (Aneshensel et al, 1995). The depression, stress and also physical health problems that may be experienced by caregivers are seen as coming from a variety of sources. There are factors related directly to the task of caregiving itself, and these are the objective and subjective primary stressors. Following Grad and Sainsbury (1965), primary stressors are seen in terms of the objective tasks of caregiving and the subjective experience of caregiving. The objective burden represents aspects of care that can be readily quantified and includes the tasks performed, the degree of cognitive impairment of the care recipient and the behavioural problems managed, including Gilleard's 'daily hassles' (Gilleard, 1984). The subjective burden refers to the caregiver's experience of providing care and is described in terms of role overload, role captivity and any loss of intimate exchange between caregiver and care recipient. Role overload is the taking on of additional tasks and roles, and role captivity refers to the degree to which the person feels trapped into providing care. The importance of this distinction between the objective reality of the situation and the caregiver's subjective experience and perceptions is increasingly recognised (Gilhooly, 1994), and will be referred to throughout this study.

### ***Does the type and severity of illness affect caregiver strain?***

A question of particular relevance to this study is that of the relative stressfulness of caring for sufferers of different illnesses. Much of the research into caregiving has been done with caregivers of dementia sufferers, however McKee and colleagues (1997) notes that it is not clear that caring for those with physical illnesses is less stressful. In particular Draper et al (1992) found no differences in the levels of strain in caregivers of dementia sufferers and stroke victims, though it may be that such a comparison is rather muddled by the cognitive sequelae of some strokes. The objective burden of

carrying out physical care is thought to be less related to stress than the subjective emotional strains (Zarit et al, 1986), and this may be why caring for someone with dementia is thought to be more stressful. In dementia, acts of 'commission' of difficult behaviours by the sufferer occur alongside acts of 'omission' in that the person is unable to perform certain activities of daily living. The objective burden of care is therefore high. The progressive loss of cognitive function means that the carer takes on increasing tasks and responsibilities leading to role overload, and there may also be a sense of losing the intimate relationship with the person. The subjective burdens may therefore heavily overlay the objective levels of care.

In physical illness it may be argued that there will be fewer difficult behaviours to manage, less interference with the relationship between caregiver and care recipient and so less experience of subjective burden. It may also be hoped that the formal services, which are set up primarily to redress the acts of omission, will alleviate much of caregiver stress in this group. However Gilleard (1984), in his study of caregivers of physically and cognitively impaired elders, found no differences in the degree of objective burden in these caregivers though they did differ in the type of problems encountered. Parker's work with 21 young married couples coping with physical disability strongly suggests the presence of some degree of adverse impact even in the absence of mental impairment in the partner (Parker, 1993). In their study of 415 older people caring for sufferers of physical illnesses, Tennstedt et al (1992) found depressive symptoms in a third of the sample. As she notes, this is indeed lower than rates generally found in caregivers for dementia sufferers, but is still twice the rate of the general population. From their review of the literature, Morris et al (1988b) suggested that incontinence, demanding behaviour and the need for constant supervision are the most stressful aspects of caregiving. These may be features of both physical and mental illness so that subjective burden will be experienced in both groups. Severity of illness is not thought to be a key factor in the burden experienced by the caregiver (Tennstedt et al, 1992). This essentially suggests that there is not a strong direct relationship between objective measures of burden and the caregivers' subjective experience. However Schultz et al (1988) have noted a positive relationship between depression and perceived burden, and the severity of the stroke.

This study will assess the well being of those caring for physically ill people as this a relatively neglected area of the literature. In line with Draper's finding it is hypothesised that elderly caregivers will experience a negative impact in terms of levels of stress and depression above that of the general population.

### ***1.1.2 Social Relationships***

Many researchers have noted the loneliness that can accompany the role of caregiver, as symbolised in Pearlin's 'secondary stressors' (Pearlin et al, 1990). Here the impact of the primary stressors on other aspects of the caregiver's life is recognised, as stressors tend to proliferate. These secondary effects are seen in the potentially negative impact on social and marital relationships. Whilst Kendler (1997) suggests that individuals may have a genetic tendency to maintain a stable level of social interaction, it seems that the role of caregiver interferes with the person's ability to do this.

In general, informal care tends to fall to one person within a family. The commitment of time and energy to the job of giving care leaves little resource for socialising outside the family for that person, and external commitments tend to be dropped (Cantor, 1983). Isolation may also stem from a sense of difference from other people, though it might be expected that this would be less an issue with older adults. Sadly, Parker (1993) notes that illness and disability can often become a barrier that separates both the ill person and the caregiver from others. In her study couples quickly became socially isolated partly due to friends 'falling away' on finding the couple less able to participate in habitual activities, but also due to the couples' own reluctance to become 'dependent' or to let others see their disability.

Miller and Montgomery (1990) also found that increasing subjective burden tends to be associated with more limited social activities. Just as perception of the caregiving situation is important, so it is that the perception of social relationships as measured against some internal ideal may be crucial. Objective measures of social activities therefore need to be supplemented with information about whether the person perceives these as adequate. Power, Champion and Aris (1988) developed the Significant Others Scale as a measure of a person's perception of the emotional and

practical support they receive. Perceptions of the actual levels are compared with the person's ideal levels in order to gain an index of likely satisfaction with the available support. It may be that the caregiver whose social relationships most nearly approach their ideal will suffer the least depression.

In this study I am hypothesising that elderly caregivers will report lower levels of social support than other populations, and that these levels will fall significantly below their ideals.

### ***1.1.3 The Marital Relationship***

Inevitably there is a unique impact of the giving and receiving of care on the relationship between the two people involved. When the two are long term partners this is particularly relevant and it has already been noted that Henderson (1977) regards the spouse as the principal source of support in elderly people. Cantor (1983) and Gilhooly (1984) note that there is increasing strain with increasing closeness of the relationship between the giver and receiver of care. Within a marriage, the concepts of caring *about* and caring *for* are even harder to distinguish so that accustomed roles and boundaries are transgressed. Illness challenges people's normal expectations of a marriage, despite the vow 'in sickness and in health'. Oliver (1983) notes that the ability to cope with each other's illnesses and to submit to intimate care from a loved one is not magically 'bestowed with the wedding ring'. In fact the evidence suggests that it is harder to care for a spouse, with spouse caregivers experiencing poorer mental health, lower morale and a greater impact on their lifestyle than other carers. They are also thought to experience a greater deterioration in their relationship with a physically frail care recipient than do other caregivers (Horowitz and Shindelman, 1983), though Johnson (1985) suggests that marital satisfaction may stand up well to physical illness. In spouse caregivers of dementia sufferers marital intimacy has also been found to be compromised (Morris et al, 1988a). Parker (1993) and Rolland (1994) note that although the marital relationship is often the prime location of care, it has been rarely studied and is almost invisible in the literature.



### ***What is the impact on the marital relationship?***

Cantor (1983) pointed out the simple fact that co-habiting can lead to a 'cabin fever' of irritability and frustration with one another. Role captivity becomes particularly relevant here as partners may feel trapped in the caregiving situation, both emotionally and physically. There may also be a certain degree of role reversal within the relationship, and this will be discussed further with regard to gender issues. However in her study, Parker (1993) argues that it is the role overload which engenders more strain, as the well member of the couple struggles to fulfil both of their roles.

In Parker's study there were no relationship breakdowns, but considerable adjustment and change had had to be accommodated within the relationship. The possibility of requiring outside help also requires the couple to negotiate new boundaries with others, and they potentially lose much of their independence. Within the relationship, illness can have particular effects on the couple's physical relationship. Parker points out the fact that embarrassment and a sense of personal dignity are not necessarily dissipated in a marital relationship, and that the provision of intimate care between partners can be very awkward for both. She also discusses the changes in patterns of dependency and power. Rolland describes these as the 'skews' that illness introduces into a relationship. The increased dependency of one partner can cross hitherto accepted boundaries, thereby altering the foundation of the relationship. This increased dependence may also result in the caregiver struggling to find a balance between watchfulness and over-protection, with the latter serving to dis-empower the disabled partner. Other inequalities may develop including the difference between being confined in many ways and being out in the world, and between being in pain and being pain free (Rolland, 1994). This latter point is also highlighted by Parker who found the experience of pain to be a considerable source of irritability within couples. The skews described threaten the balance of exchange within the relationship, and this can lead to resentment and guilt. Parker suggests that the caregiver will have to re-evaluate the relationship or their view of their partner in order to maintain the relationship.

The particular difficulty of coping with caring for a spouse is that the basis of the relationship is a caring about each other. In Parker's view this denies the carer the

useful coping strategy of emotional distancing, without negating the relationship. As mentioned earlier, theories of attachment are of relevance here. Weiss (1974) suggests six provisions of relationships; the provision of attachment, social integration, the opportunity to nurture others, reassurance of worth, a sense of a reliable alliance and obtaining help and guidance. Illness in a partner challenges some of these provisions and may therefore reduce the sense of attachment, thereby threatening the relationship. Hansson and Carpenter (1994) discuss the impact on the relationship in terms of a cost-benefit analysis, describing Weiss's six provisions as the benefit. The costs of gaining these provisions are in terms of instrumental demands, compromise and emotional vulnerability. In the caregiving situation, these costs are perhaps more prominent and some of the benefits are lost. Hence the caregiver gains less from the relationship, thereby engendering a need for care. Cantor (1983) notes that spouses may feel neglect themselves as they find themselves in an increasingly 'one way' relationship, and this is in line with Henderson's work (1974) on the 'care eliciting' syndromes or neuroses.

The potential loss of marital intimacy will have its own effect on levels of mental health, with Waring and Patton (1984) noting a significant relationship between marital intimacy and depression. Trezise (1986) also found higher rates of depression in spouse caregivers where loss of intimacy was greater. Similarly Parkes and Stevenson-Hinde (1982) found an inverse relationship between scores on the General Health Questionnaire and the presence and perceived adequacy of attachments. They also noted that it was the perception of adequacy that was crucial rather than the objective presence of such attachments per se.

### ***What factors mediate the impact on the marital relationship?***

The factors that appear most strongly to protect a marriage in this situation are the quality of the marriage before the illness, a sense of reciprocity and duty, as well as the personality and experience of the caregiver.

Many researchers would hold that a good relationship prior to the onset of disease would predict lower strain in the caregiver. This is based on research with caregivers of various relationships to the recipient, and holds with caregivers of both dementia sufferers (Gilhooly, 1984) and the physically ill (Horowitz and Shindelman, 1983).



In her interviews with 125 couples over the age of eighty, Wenger (1987) also found a high degree of interdependence within these couples caring for each other in the community. Trezise (1986) looked specifically at spouse caregivers of dementia sufferers and found an inverse relationship between the degree of past intimacy and the current caregiver strain. She hypothesised that couples with high levels of previous intimacy looked after each other from a sense of affection and desire to care, rather than from a sense of duty. A key facet of the eight components of intimacy described by Waring and Reddon (1983) is open communication, and it may be that this helps the partners to negotiate the changes described above. In their study of 203 caregivers to the frail elderly, Horowitz and Shindelman suggested that caregivers are generally reciprocating in the context of past care from the current care receiver. Like Trezise, they note lower levels of caregiver strain with greater levels of affection within the relationship. Here they seem to suggest that the quality of the past relationship is perhaps providing an enduring 'benefit' as in Hansson and Carpenter's analysis. This then allows a relationship to stand up to the stress of caregiving.

A sense of duty and obligation is also highlighted as a reason for adopting a caregiving role within a marriage, and as such may also be used as a coping strategy (Fitting, 1986). However, Horowitz and Shindelman suggest that a sense of 'repaying debts' in the relationship may enhance the amount of help a caregiver may be prepared to give, but does not have an effect on the level of strain they experience. There may be cohort effects in this, with Askham (1995) suggesting that marriage is now seen less as an immutable institution and more as a fluid interdependent relationship between individuals. It may then be expected that the current cohort of older couples will be more likely to cite obligation to vows and duty as a reason for caring.

Hansson and Carpenter (1994) introduce the idea of 'relational competence' as representing the characteristics of a person that facilitate mutually satisfying relationships. This gives the obvious caution that coping and relationship survival are dependent on individual personality. Returning to attachment theories, Ingebreton and Solem (1995) describe how an individual's experience of care as a child may effect their giving of care to their dementing spouse. They suggest that an experience

of insecure attachments may lead the caregiver to pressurise their partner to be well and so to return to them, or to withdraw from their partner and avoid the pain of the lost relationship. The implication is that caregivers who have developed from a secure attachment base will be more able to adapt to the changing provisions and demands within their relationship.

The impact on the marital relationship has implications in terms of considering caregiver strain, but also in terms of predicting or anticipating the breakdown of the caregiving situation. Spouse caregivers have generally been found to be less likely to seek institutional care (Gilleard, 1984; Gilhooly et al, 1994), and may therefore be seen as a valuable resource. In order to support couples in the caregiving situation, it is important to understand their experience. In this study I am hypothesising that elderly spouse caregivers will experience low levels of marital intimacy, and I am aiming to qualitatively explore their perceptions of their role and its changes.

## **1.2 The Role of Psychosocial Resources**

It has already been noted that the objective burden of care is not directly related either to the subjective experience or to the outcome in terms of caregiver well being. Psychosocial resources, in terms of the individuals' perceptions of their situation as well as the personal and social assets of the individual, may modify the psychological impact of caregiving.

The importance of individual perceptions is increasingly recognised, particularly how the caregiver perceives the burden and the help they receive. These perceptions can mediate the impact of caregiving on self-esteem and self-concept, as caregivers will differ in their expectations of help and in their level of optimism (Schultz et al, 1988). In her study of spouse caregivers, Trezise (1986) looked specifically at the role of attributions in caregiver strain. She found that increased strain was associated with a tendency to attribute a dementing person's behaviour as due to global and stable factors thereby leaving little expectation of change or relief. A feeling of loss of control and inability to cope with the situation was also associated with higher rates of depression and strain. On a happier note, there are those who make positive

attributions regarding the caregiving role, for instance people often choose it and obtain significant reward from it. It has already been noted that caregivers may gain satisfaction from their role where there is a good relationship with the care recipient, and Schultz et al (1990) also point out that the caregiving can actually serve to improve that relationship in some cases. Other attributions that may foster a positive view of the caregiving role include gaining a sense of satisfaction in the mastery of the new role, seeing the act of caregiving as part of following one's faith and seeing oneself as 'the best person for the job' (Nolan and Grant, 1992).

Personal assets would include the individual's coping styles and strategies. It has been suggested that individuals adopting problem focussed coping strategies, as opposed to emotion focussed strategies, will experience lower levels of stress in the caregiving situation. The less effective emotion-focussed strategies include suppressing or expressing emotions, or displacing them onto other activities such as eating, without working through the problem or searching for solutions. The problem-focussed strategies include accepting support, talking through the problem or altering practical constraints. The literature on coping is well reviewed by McKee et al (1997) and will not be detailed here, as it is not within the scope of this study.

Social assets are essentially the amount or quality of support available to the person and have been found to play an important role in reducing psychological distress in caregivers (Avison, 1993). The long term effect is thought to be to offset the stress of role captivity and the loss of intimate exchange in the caregiving relationship. Support is commonly divided into instrumental and emotional help from formal or informal sources. Formal supports tend to provide help with specialised and predictable tasks, whereas informal caregivers tend to perform the non-technical and unpredictable tasks (Noelker and Bass, 1989). Researchers have commonly noted a substantial unmet need for assistance in caregivers, particularly in terms of instrumental support (Aneshensel et al, 1995). This is thought to be particularly so for spouses (Wenger, 1987). This is presumably because others assume that adequate emotional support is gained within the relationship, though this is not necessarily the case as has been discussed above.

### ***1.2.1 Social Relationships and Informal Support***

A principal difficulty in examining the beneficial effects of social relationships in the caregiving situation is that the caregiving itself can interrupt channels of emotional support as described above. The interaction between support and psychological well-being is also difficult to conceptualise or to develop a coherent model for. There are also methodological difficulties, particularly in terms of measuring support adequately and over an appropriate time period (Power, 1988).

Gallo (1990) provides a useful model of the components of informal social support, and he distinguishes between quantity and quality of support. This once again highlights the difference between objective quantification of the numbers of contacts or range of supports, and the subjective experience of the function of that support for an individual. Although the former is more readily measured, it is the latter which provides the reference standard by which adequacy must be judged. There is considerable support for the notion that perceived adequacy may be a more critical factor in predicting outcome variables than objective measures of support (Parkes and Stevenson-Hinde, 1982; Gallo, 1990; Lam and Power, 1991). An additional factor in the measurement of support is the lack of agreement between researchers as to whether the entire network of social relationships can be thought of as supportive, or whether there is a subset of qualitatively different 'supportive' relationships (Scott and Wenger, 1995).

#### ***By what mechanism does social support affect mood?***

There are three competing models that describe how social support may protect against depression. The first two would hold that a lack of social support is only pathogenic in the presence of adversity.

The *buffering model* holds that support acts as a moderator against the impact of a stressful situation, that is it interacts with the stressor to indirectly reduce its effect on the person's well-being. This is similar to Brown and Harris's seminal work on depression in young women (Brown and Harris, 1978). They found that the presence of an intimate confiding relationship in the face of stressful events was related to a

lower incidence of depression. As already noted, Waring similarly found an inverse relationship between marital intimacy and depression (Waring and Patton, 1984).

The second *mediation model* holds that the influence of stress is mediated by support, that is the stress impacts upon the support network and this in turn affects the well-being of the person. Under this model there are three possible effects of stress. Firstly the support network may resist the effects of the stress and so protect the person's well-being (stress deterrence). This model would be supported by Kendler's work suggesting that a person's need and use of social support is genetically defined and hence fairly stable over time (Kendler, 1997). However, this would contradict the work reviewed above which suggests that caregiving does have a significant impact on a person's social network. Secondly the support network may be mobilised at times of stress and this then positively affects well-being (stress suppression). Thirdly the impact of stress may be to deplete sources of support which then directly and negatively affects well-being (the deterioration model).

The third *main effect* model holds that there is a direct positive effect of social support on mood, independent of any stressors. This model fits with attachment theories that would hold that the need for social relationships is fundamental. Relationships fulfil the provisions of attachment, and so directly contribute to the individual's well-being. Further, Hansson and Carpenter (1994) note one of the direct benefits of a relationship as facilitating adaptive coping within the individual.

In their study of the caregiving career Aneshensel et al (1995) found no support for a mediating or moderating effect of support, but rather found an independent main effect of support on well-being. This independent effect was also found in a review of studies on caregiving (Avison et al, 1993). In this way socio-emotional support is thought to fulfil a person's needs for attachment and therefore to exert an independent, positive effect on mood. Psychosocial resources therefore matter in themselves irrespective of other stressors and in fact may have an active role in contributing to stress levels if they are absent, rather than the reactive role posited in the first two models. This model is not exclusive of the buffering model, as support could have the direct, positive effect on well-being, as well as modifying the effects of stress. This is also pointed out by Henderson (1977) who notes that relationships have an essential function in their own right, but come to be called 'support' when

used in stressful situations. The difficulty in studying the positive effects of support is that a lack of social support is of itself a secondary effect of depression (Aneshensel and Stone, 1982). Depression then becomes itself a stressor that depletes support according to a deterioration model.

### *Social support and elderly spouse caregivers*

Beyond these theoretical questions, Parker (1993) found that receiving support was not a simple matter of accepting what may be on offer. The couples she interviewed were reluctant to accept help from others if they were unable to reciprocate or if they felt that acceptance of help destroyed normal social boundaries. The couples found it easier to accept help from churchgoers where they felt there was no pressure to reciprocate, rather than from friends. They tended to resent accepting help from neighbours, feeling that this broke down desirable boundaries around the privacy of their home. There was also much concern about 'being a burden' particularly with regard to accepting help from their children.

This may be particularly an issue with older people. Gallo (1990) suggests that the elderly are reluctant to mobilise support from others, even if they feel it is there. He further suggests that older people are overly optimistic in a hypothetical assessment of the help available to them. This is in contrast to findings that older people have fewer close relationships than younger people, but are no less satisfied (Wenger, 1987). In a similar vein, Lam and Power (1991) found that the majority of their general practice based sample of older adults reported satisfaction with the support they perceived to be available to them. Indeed almost one third of the sample said they received more than enough support. In a stressful situation such as caregiving it may become clear whether or not this perception is justified by examining satisfaction in that situation. Morris et al (1988b) point out the practical implications of any reduction in social support in that the caregiver is likely then to seek greater levels of formal support.

In this study I am hypothesising that the level of stress and depression in elderly spouse caregivers will be related to their perceptions of their social support and marital intimacy. Using a longitudinal design, I will be examining to what extent the levels of these supports predict stress and depression over time.



### ***1.2.2 Formal Services***

In general, formal services are set up to provide support and respite. Services directed specifically at caregiver support would include support groups and the availability of psychotherapy or counselling. Those directed at respite would relieve caregivers of some portion of their care activities, such as day care, in-home services or institutional respite. These services would include health services, social services, private and voluntary sector provisions.

This study is centred on caregivers of partners attending day hospitals. Day hospitals are seen as a major component of health services for the elderly (Gilleard, 1984). However, there is a lack of evidence that day hospitals generally are the best use of resources and there has been some debate about their future (Howard, 1994). They are expensive and they frequently provide low-intensity activities that could be provided by cheaper alternatives. Proponents of day hospitals see them as having six major advantages for service users and argue for the day hospitals remaining as an option for referrers (Howard, 1994 and Gilleard, 1984). They provide an alternative to both in-patient admission and long term care, they provide respite for the caregiver, they both assess and monitor patients and they allow the maintenance of other services provided within the community. In a survey of 92 elderly patients and carers attending medical day hospitals, Stephenson et al (1995) found high rates of satisfaction with day hospital services in terms of patient enjoyment, patient improvement and carer respite. Gilleard notes that the majority of medical day hospital users suffer from strokes and arthritic disorders.

Noelker and Bass (1989) undertook a large survey of caregivers to investigate how formal and informal services link in the community. They found that the commonest situation was that of kin independence whereby the caregiver was essentially managing alone and almost refusing help. The use of formal services was limited either to carrying out specialist tasks or providing respite. The lack of service use has been noted in other reviews (Parris Stephens, 1993), and the couples in Parker's study similarly received a very low level of formal help. However there was a great sense of unmet need for respite (Parker, 1993). Two important issues when

considering the use of formal services are the factors that govern their uptake by caregivers and the degree to which they succeed in relieving caregiver strain.

The Andersen model of service use provides a framework for understanding the factors impeding service uptake. These factors may relate to personal characteristics, demographic factors or to subjective or objective assessments of need for care (Andersen and Newman, 1973). It is this latter group of factors which most strongly predicts service use, and Parris Stephens argues that it is once again the person's perceptions and cognitions which are more important than objective measures of need. She suggests that caregivers will seek help if psychologically distressed, but that the ambiguous and fluctuating nature of mental health symptoms may make them hard for an individual to identify. The caregiver may then not seek help, or even if they do recognise their distress may be impeded in taking up services by feelings of guilt or even lack of knowledge about services available (Parris Stephens, 1993). It has also been suggested that the current cohort of older adults are particularly reluctant to seek formal help, seeing 'welfare' as stigmatising and also feeling themselves to be well off relative to other times in their life (Qureshi and Walker, 1989).

Research has suggested that it is the emotional demands of caregiving that are most linked to caregiver strain, and it may be expected that the practical help of formal services would therefore not relieve the caregiver's burden. Indeed studies have found no relationship between formal care and levels of depression and stress (Gilleard, 1984). Still others have found a positive relationship between caregiver strain and formal support (Trezise, 1986), though this finding may be explained in terms of increased help seeking by caregivers who are most strained. These studies are with caregivers of dementia sufferers, and it has already been noted that it is the acts of commission which are the most difficult aspects of dementia. There are also studies suggesting that neither formal nor informal support have any effect on depressive symptoms in other caregiver populations (Tennstedt et al, 1992). In a review of day hospital services Gilhooly (1990) concludes that for dementia sufferers they act as a supplement to institutionalisation rather than an alternative and takes the position that they *should* be supplementary in order to reduce the burden of care on the families. It may be hoped that the help with acts of omission provided by formal



services will be of more help for caregivers of those with physical illness. It may also be expected that there would be an indirect effect of increased time for the caregiver allowing a greater investment in emotional relationships both inside and outside the caring relationship. For those services such as day hospitals which provide a time limited service, it may be hypothesised that the relief that they may bring to caregivers might also be limited to the time that they run. However it may be hoped that the caregiver may be able to use the service to 'shore up' their other supports and so maintain the benefits of the temporary respite.

In this study I am hypothesising that their partner's attendance at a day hospital will alleviate depression and stress in the caregiver. The degree of this change will be related to the caregiver's perception of the helpfulness of the service, but will also be predicted by their perceptions of the adequacy of their own social supports. I also hypothesise that mental health will again decline weeks after the day hospital intervention, but not to below the initial levels.

### **1.3 Gender**

According to Pearlin et al's model, factors related to the background and context of the individual play a role in the experience of stress. Gender is one such factor and studies of gender differences in caregiving have moved from the feminist critique of the 1970's, towards a greater recognition of the male role in caregiving. As study has evolved, the emphasis has shifted to the differences in experiences of caregiving and how these may be explained.

#### ***1.3.1 The Politics of Gender in Caregiving***

The early feminist critique of informal care acknowledged women as the principal carers, with a view that care in the community was exploitative of women. In her study Parker (1993) observed that men's needs and preferences were addressed before the women's in each couple regardless of who was the caregiver. She describes how female caregivers are encouraged to provide all care for their partner,

not least to protect him from the awkwardness of receiving intimate care from another. On the other hand, disabled women are more likely to feel obliged to accept care from a stranger to spare their partners from taking on an unaccustomed role. Aronson (1990) also speaks of a 'cultural imperative' for older women not to be a burden. This may be in part a cohort effect, with gender stereotypes perhaps more strongly held in the current generation of middle aged and older adults. Although Fitting (1986) has warned against succumbing to gender stereotypes, Parker hypothesises that women expect to provide domestic support and men to provide financial support, and each will feel guilty when accepting help that they would normally provide. Following from this male caregivers are thought to be more likely to receive and accept outside help instead of performing caregiving and domestic tasks themselves, whereas women tend to accept more limited help as a supplement to their own efforts (Noelker and Bass, 1989). It may be that men accept help more readily than women, but Parker (1993) and Oliver (1983) would argue a social and an internal pressure on women to accept their caring role as part and parcel of their gender. The 'labour of love' that is caregiving is adopted by women and is said to define both their identity and their activity (Graham, 1983).

However in 1994 Fisher wrote that male carers had been 'discovered' in equal proportions to female carers in the older population and in their survey of 306 caregivers, Qureshi and Walker (1989) found that the majority of the spouse caregivers were male. Although women tend to live longer and to marry men older than themselves, thereby making it likely that they will become caregivers, women also tend to have poorer health in their extended life span so that husbands are equally often found to be caregivers. Fisher notes that marital status and not gender is of prime significance in the 'obligation to care', and he argues that male spouse carers suffer similar struggles to female carers. In a similar vein Wenger (1987) suggests that it is not that women are undervalued because they are caregivers, rather it is caregiving itself that has tended to be undervalued. However, there is a political slant to this as she also suggests that caregiving is undervalued because it has traditionally been done by women. Despite recognition of their role by some researchers, male caregivers have tended to be marginalised, certainly in the literature, and thought of as providing simple instrumental help without the moral

and emotional commitment. Rose and Bruce (1995) quote the General Household Survey of 1985, and also suggest that older male spouses do as much caregiving as do women. However, in their study of 16 older couples they looked specifically at gender differences in attitudes to care and found that male caregivers tended to regard themselves and to be regarded by others as performing a 'special' task as opposed to the 'natural' role of the female carers. Parker notes that the difference between what women normally do and what they do in the caring situation is less obvious than for men, hence for women caregiving may be seen as natural whereas for men it may be more regarded as a job. The perspective of feminist writers is to ask the question 'do men care less and cope better?' (Rose and Bruce, 1995).

### ***1.3.2 Gender Differences in the Experience of Burden***

It has been found that overall men initially experience less burden as caregivers than do women (Fisher, 1994; Gilhooly, 1984; Schultz et al, 1990, and in her study of 54 older spouse caregivers for dementia sufferers Fitting (1986) found higher levels of depression in the wives. However Zarit et al (1986) suggest that the degree of burden evens out over time, and Wenger (1987) has also suggested that caregiving would in fact be expected to be more burdensome for husbands as they tend to be older and to care for longer. It is also possible that the apparent early coping of male caregivers is simply an issue of underreporting as in other areas of mental health (Gilhooly, 1984). Men tend to report fewer psychological symptoms than women do and may express their distress in ways less likely to be recognised as such, for example in drinking. There is some disagreement amongst researchers over which aspects of care are more difficult for men and women. It has been suggested that women experience more of the subjective burdens such as feeling 'trapped' in their role (Fitting, 1986) and that they mourn the socio-emotional losses, whereas the men find the objective, physical demands most stressful (Wenger, 1987). Others have hypothesised the reverse; that women struggle with the heavy physical demands (Gilhooly, 1984) and in the case of dementia men mourn the loss of intimate exchange with their partner (Zarit et al, 1986). The gender differences found in experience of burden have therefore been explained in different ways by different researchers. These explanations fall into

three main types; those to do with gender roles, gender coping and gender differences in social relationships.

***Gender roles, coping and differences in social relationships.***

Wenger hypothesises that men are adopting a role which may be against their expectations from life, and they are then likely to experience dissonance and stress. In a similar vein, Aneshensel and colleagues describe women, but not men, as reporting that they had gained something from the caregiving role. In contrast to this, those finding a lesser degree of subjective burden in men have tended to explain this in terms of a 'welcome change' in role. Women tend to move away from their caregiving role later in life, and adopt more 'masculine' characteristics of independence and autonomy. They are thought to have more roles available to them than earlier in life (Wilson, 1995). On the other hand men are thought to become more 'feminine' with age, placing an increasing importance on interdependence and care within the marital relationship. Women are then thought to resent the return to a mothering role, whereas men enjoy the chance to express the nurturing aspects of themselves. In her study of nineteen caregivers, Ungerson (1987) noted that the only male caregivers were retired, again suggesting that men adopt the role more readily later in life. It is hypothesised that although gender roles persist until late life, there does tend to be more flexibility in stereotypes beyond a certain age (Wilson, 1995). Role reversal is therefore thought to be part of normal ageing, and it is in fact the lack of this reversal that causes stress in older female caregivers and the presence of reversal that helps older male caregivers to cope. Fitting (1986) also found that a quarter of the husband caregivers she interviewed felt that their relationship with their wife had improved as a result of the intimacy and reciprocity. This would then leave male caregivers vulnerable to feeling the loss of this new exchange in the case of dementia (Zarit et al, 1986).

In terms of gender coping, it has been suggested that female caregivers may tend to adopt the 'mothering role' (Parker, 1993; Ungerson, 1987). Gilhooly (1984) suggests that women may then become emotionally over-involved in the caregiving role. Ungerson (1987) suggests that female caregivers adopt the caregiving role passively, out of a sense of duty and to avoid guilt. They are less likely to put their partner at

risk even in order to protect their own mental health, for example by leaving the person alone in order to have time for themselves. Female caregivers tend to adopt emotion focussed coping strategies, which are not thought to be effective in this practical task (McKee et al, 1997). Men on the other hand are thought to see caregiving more as a 'job' or at least as a repayment to their wives for past care (Fitting, 1986). It is also thought that they adopt the role actively, and gain a sense of personal competence by viewing the role as a job (Ungerson, 1987). They then tend to use more problem focussed coping strategies which have been found to be more successful in reducing stress in the caregiving situation (McKee et al, 1997).

Interestingly Fitting (1986) found that there was no difference between husbands and wives in terms of the amount of social support they had available. This goes against Scott and Wenger's view that women have a wider supporting network with longer lasting relationships that would be expected to give them a 'psychosocial advantage'. It may be that the tendency of female caregivers to use more emotion-focussed strategies weighs against this advantage. These additional supports may not be helpful if they are being used to offload negative emotions rather than talking through difficulties. In addition the relatively well-established finding that marriage is more beneficial for men than for women would also tend to weigh against the benefit of a wider social network. It is interesting to refer back to Henderson's work which anticipates the greater negative impact on mental health in female carers because they will respond adversely to any loss of care from others and their partner. In this study I am hypothesising that female caregivers will report higher levels of depression and stress than males, and lower levels of marital intimacy. I am also hypothesising that male caregivers will report less dissatisfaction with levels of support and that there will be a weaker relationship between mood and relationship measures than in women.

## 1.4 Methodological Issues

This review of the literature suggests three important points in considering research into caregiving. These are the view of caregiving as an on-going process, the importance of qualitative data and the need for appropriate sampling.

Studies of caregiver stress have sometimes failed to take account of the fact that caregiving is an on-going process. Some theories suggest that there are stages of the caregiving process, each with unique difficulties. Aneshensel et al (1995) talk simply of role acquisition, role enactment and role disengagement. Schulz et al (1988) followed the primary support person of stroke victims over the first 6 months after the stroke and found that depression did not change over that time but that optimism declined. Use of services also changes over time (Noelker and Bass, 1989), particularly with an initial reluctance to receive any help. The important point is that the process is not static or chronic, but waxes and wanes with episodes, crises and an unknown ending point. Single time point research will fail to capture this process. The importance of longitudinal study of caregiving also lies in teasing out the direction and mode of causality of some of the relationships found. For example, does social support predict better mental health, or is it that those caregivers with better mental health tend to maintain their social relationships?

The importance of qualitative data has been emphasised throughout this review. An understanding of caregiver perceptions and the subjective experience of caregiving is needed to supplement objective measures taken. This is partly because this subjective experience is thought to be better related to outcome measures. Also, a qualitative approach allows more consideration of the individuals' reasons for caregiving and their views on the pitfalls and also benefits of their role (Morris et al, 1988b).

If such data is to be included, the homogeneity and appropriateness of the sample is particularly important (Schultz et al, 1990). There is a call for population-based studies to minimise the self-selection biases of volunteer studies. However, such large scale studies have their own methodological difficulties. An alternative is to recruit samples from circumscribed populations in order to represent a particular set of caregiver experiences.



Smyer (1993) uses the metaphor of 'juggling while walking' to describe how caregiving research is best done. The researcher must 'juggle' (or at least consider!) the various aspects of caregiving as described in Pearlin's model, and as reviewed here. He must then walk with his conceptual model in order to see how it may change over time.

## **1.5 Aims**

I aim to investigate the impact of caregiving on mental health and social relationships. I also aim to explore the role of informal and formal supports in mediating against depression and stress in caregivers. This is a longitudinal study, with the researcher meeting with caregivers on at least two occasions in a three month time frame, in order to try to make clear the causality of any effects found. Qualitative data will be used to supplement more objective measures, and the emphasis throughout the study is on self report and the importance of the participants' perceptions. The sample in this study is defined as elderly spouse caregivers, and because of the bias in the literature I am confining the sample to those caring for physically frail partners.

## **1.6 Hypotheses**

### **1. The impact of caregiving**

Caregiving will have an impact on the caregiver's mental health and social and marital relationships. Specifically, caregivers will have levels of stress and depression above the general population, a discrepancy between perceived and ideal social support, and low rates of marital intimacy

## **2. The relationship between mental health and psychosocial resources**

The level of stress and depression in caregivers will be related to their perception of their social support and marital intimacy. Specifically, the higher the discrepancy between perceived and ideal social support and the lower the marital intimacy, the higher will be the levels of stress and depression.

## **3. Predictors of change in mental health over time**

When controlling for changes in the partner's illness, changes in the caregiver's illness and other adverse life events over this period, there will be a reduction in rates of depression and stress in the caregiver after their partner has attended a day hospital. This change will be principally predicted by caregivers' initial perceptions of social support and the marital relationship as well as by their satisfaction with the service.

Again controlling for other events, following their partner's discharge from the day hospital caregiver depression and stress will rise, but to levels below the initial levels. Once again this change will principally be predicted by caregivers' initial perceptions of social support and the marital relationship as well as by their satisfaction with the service.

## **4. Gender**

Females will have higher levels of stress and depression and report lower levels of marital intimacy than males, due to the difficulty of returning to an old and 'devalued' role.

Males will have lower actual and ideal levels of support, smaller discrepancies between the two and a smaller correlation between mood and measures of relationships than females.



## **2. METHOD**

This study was approved by the Lothian Research Ethics Subcommittee (Psychiatry and Clinical Psychology), 31 December 1997.

### **2.1 Design**

A longitudinal design is used and quantitative data are analysed in a within-subjects design over three time points. Correlations, multiple regression analyses and comparative statistics are used, including comparisons with normative data. Qualitative data are thematically analysed.

### **2.2 Participants**

#### ***2.2.1 Recruitment***

Participants were initially recruited from a medical day hospital attached to a hospital for older adults. New referrals were checked daily to discover if they had a spouse at home. If so, a letter of introduction including research information, a consent form and a provisional appointment were sent to the spouse (see Appendix 1). The voluntary nature of the study was emphasised and potential participants were encouraged to telephone if they required further information, an alternative appointment or a home visit. Due to small numbers, recruitment was subsequently increased to include four other day hospitals within the Lothian region, two of which were outside Edinburgh. The recruitment procedure remained unchanged for these additional sources. Those who attended the appointment were included in the study provided that they were over 60 years old and regarded themselves as the caregiver of a physically frail partner. Those caregivers whose partners had significant cognitive impairment or dementia were excluded. This was ascertained by asking the caregivers and by checking day hospital notes. Efforts were made to contact all of

those who did not attend the appointment in order to assess their level of strain. The researcher telephoned them, acknowledged their right not to participate but asked if they would be prepared to answer one question over the telephone.

### *2.2.2 Sample Size*

30 spouses were recruited from 76 introductory letters.

Of the 46 who were not selected 23 failed to attend the appointments offered, 18 declined to participate in the study and 5 were seen but did not meet criteria for selection. This latter group included 4 spouses who did not regard themselves as providing any care for their partners and 1 spouse whose partner was significantly cognitively impaired.

Due to difficulties in chasing up the 46 non-attendees, only 17 were contacted but all of these responded to the strain scale.

19 of these participants were followed up a mean of 6.20 (SD = 2.21) weeks later.

Of the 11 who were not followed up, 3 had partners who never went on to attend a day hospital, 2 had partners who went into hospital with significant further illness, 1 declined to participate further and 5 were seen too late in the study for follow up.

7 of these participants were followed up again a mean of 6.51 (SD = 1.43) weeks later.

Of the 11 who were not followed up a second time, 1 had a partner who went into hospital with significant further illness and 10 were seen too late in the study for follow up.

A breakdown of the number of letters sent and spouses recruited from each day hospital is given in table 2.2.2. It can be seen that the highest recruitment rate was from the day hospital on which the study was based. Interestingly the out of city day hospitals did not necessarily have the lowest recruitment rates despite the increased distance, though more home visits were made.

Day Hospital		Number of letters sent	Number of spouses recruited	Recruitment rate	Number of Home Visits
Initial Day Hospital (City)		37	19	.51	6
Day Hospital 2 (City)	2	12	4	.33	1
Day Hospital 3 (City)	3	8	1	.13	1
Day Hospital 4 (Outside)	4	11	2	.18	2
Day Hospital 5 (Outside)	5	8	4	.50	3
<b>Sum</b>		<b>76</b>	<b>30</b>	<b>.39</b>	<b>13</b>

**Table 2.2.2; recruitment patterns across the five day hospitals.**

### *2.2.3 Sample Characteristics*

Basic demographic data for the sample information were gathered during the first meeting with the participants and are shown in table 2.2.3. The deprivation measure was obtained using the Standard Occupational Classifications (1990). Where the couple both worked, the higher occupational status was taken. The services mentioned were district nurses, home helps, private cleaners, provision of aids and adaptations, respite services and ‘tuck in’ services. It can be seen that roughly two thirds of the sample were female, that this is not a new group of caregivers and that they receive relatively little help, with a mean of one service per couple. It can also be seen that the characteristics of the sample did not change greatly over the three time points. This was tested and the changes were indeed found to be non-significant. A Chi squared test was used to test for differences in gender proportions across the samples ( $\chi^2 = 0.238$ ,  $df = 2$ ,  $p > 0.05$ ). One way ANOVAs were used to test for differences in age, number of years as a carer, number of services involved and deprivation ( $F = 0.230$ ,  $0.827$ ,  $1.493$  and  $3.081$  respectively,  $df = 2$ ,  $p > 0.05$ ).

	Time 1	Time 2	Time 3
<b>Number</b>	30	19	7
<b>Percentage of Females</b>	66.7	63.2	57.1
<b>Age</b>	74.57 (5.8)	74.05 (6.1)	73.57 (5.9)
<b>Deprivation Measure</b>	3.93 (2.6)	3.11 (2.3)	3.00 (2.9)
<b>No. Years caregiving</b>	3.39 (4.3)	3.75 (4.7)	2.27 (1.3)
<b>No. of Services</b>	1.00 (1.0)	1.21 (1.1)	1.00 (1.0)

**Table 2.2.3; sample characteristics at each time point.**  
(where means are quoted, standard deviations are given in brackets).

In addition to the information shown in the table, 40% of the participants had had previous experience of caregiving and 43% were taking medication themselves. With regard to the partners' illness, many had multiple illnesses. The most common was stroke (43.33%), followed by other vascular problems (16.67%) and joint or bone problems such as arthritis and osteoporosis (16.67%), followed by Parkinson's disease, ischaemic heart disease and respiratory problems (all at 13.33%).

It was not always possible to see participants before their partner had begun attending the day hospital. The recruitment procedure was often slow because ample time was allowed for potential participants to consider whether they wanted to take part or to arrange a home visit. Participants were seen after their partner had attended a mean of 1.73 (SD=1.17) times at the day hospitals.

## 2.3 Measures

### 2.3.1 Mental Health and Experience of Strain

#### *Geriatric Depression Screening Scale – Short Form (Sheikh and Yesavage, 1986)*

This is a fifteen item scale with a simple 'yes' / 'no' answer format (see Appendix 2). It was derived from the original 30 item scale and includes the items which had the highest correlations with depressive symptoms in validation studies of the longer form. It correlates well with the longer form and a cut off score of 5 has been found to yield 65% specificity and 70% sensitivity (Cwikel and Ritchie, 1988).

This scale (GDSS) was administered to all participants at each time point.

### ***General Health Questionnaire – 28 (Goldberg and Hillier, 1979)***

This instrument was designed as a screening questionnaire to differentiate psychiatric patients from those who consider themselves to be well (see Appendix 3). It is frequently used as a research tool as it provides a general measure of severity, but also subdivides into four subscales (somatic symptoms, anxiety and insomnia, social dysfunction and severe depression). It has been shown to have good specificity (88%) and sensitivity (84.2%). In this study the simple scoring method of the four response categories (0-0-1-1) is used rather than the Likert method. The threshold score of 4 / 5 is taken, with scores above 5 indicating psychiatric caseness.

This scale (GHQ) was administered to all participants at each time point.

### ***Likert Scales – strain and optimism***

These are seven point Likert scales with the lower ends of the scales representing lower strain and increased optimism (see Appendix 4). The strain measure was taken from Morris et al (1988) and was added to provide a measure of strain specific to the caregiving situation. The optimism measure was devised by the author following Schultz et al (1988)'s finding that optimism in caregivers of stroke patients declines over time. It should be noted that the optimism scale is drawn up to correspond to the other Likert scales so that high scores represent the 'negative' end, in this case pessimism. However the naming of the scale in positive terms ('optimism') can be confusing in the description of analyses.

These scales were administered to all participants at each time point.

## ***2.3.2 Subjective Stressors***

### ***Role Overload, Role Captivity and Relational Deprivation (Pearlin et al, 1990)***

These are three subscales from a set of measures designed to complement Pearlin's model of caregiver stress. The measures were constructed from factor analyses of data gathered from 555 interviews with caregivers of people with dementia. The subscales comprise 3 – 6 items answered by selecting one of four response categories (see Appendix 5). Scoring of each item is from 1 to 4, with 1 indicating a lack of

stress. The reliability of the subscales range from alpha co-efficient .67 - .83, and mean responses for each item are given. These particular subscales were selected to represent the subjective burden of caregiving as described in the introduction.

This scale (PSS) was introduced to the study after 6 participants had already been recruited. It was brought in because the measures above did not appear to be sensitive to change over time and it was hoped that a measure more specific to the caregiving situation would be more sensitive. All 3 subscales were administered to subsequent participants at time 1. The relational deprivation scale was excluded at time 2 as it was considered that this scale measures a more stable construct. The PSS was not administered at time 3 due to time constraints.

### ***2.3.3 Objective Stressors***

#### ***Gilleard's Problem Checklist (Gilleard and Watts, 1982)***

This is a comprehensive list of 35 potential stressors facing caregivers including deficits, disturbances and disabilities (see Appendix 6). It was designed for use with caregivers of dementia sufferers, but has also been used by Gilleard in a comparative study between supporters of mentally impaired and mentally unimpaired day hospital patients (Gilleard, 1984). In its revised version the scale comprises two subscales; the occurrence and frequency of potential stressors and the identification of them as 'problematic' by the caregiver. In this study the checklist is simply used to identify the occurrence and frequency of the problems from never (0) to occasionally (1) to continuously (2). Following Gilleard, three subscales are also derived from the scale – communication problems, behaviour disturbance and mobility problems.

This scale (GPCL) was introduced to the study after 1 participant had been recruited as it was quickly recognised that there were insufficient data on the partners' problems. It was administered at time 1 only and was therefore not used as a measure of change over time.

### ***2.3.4 Social Support and Marital Intimacy***

#### ***Significant Others Scale – B (Power, Champion and Aris, 1988)***

This scale requires the respondent to rate up to seven significant others on their provision of emotional and practical support (see Appendix 7). Two emotional and two practical support functions are assessed, with the respondent rating both actual and ideal levels of each support function for each person chosen. A seven point rating system is used, ranging from never (1) to always (7). This yields six summary scores; actual emotional and practical support, ideal emotional and practical support and discrepancies between actual and ideal levels of the two support functions. In addition it is possible to calculate these summary scores for each significant other. In this study the summary scores were also calculated for the spouse, where participants had rated their spouse (n=24). Test-retest reliability over six months ranges from 0.73 to 0.83 across the summary scores. Mean ratings are available for small groups of depressed patients, Parkinsonian patients, caregivers, older adults and students. This questionnaire (SOS-B) was administered at time 1 only as it was considered unlikely to vary significantly over the time scale of the study.

#### ***Marital Intimacy Questionnaire (Morris et al, 1988)***

This was developed specifically for use with elderly spouse caregivers, from the definition of intimacy devised by Waring and Reddon (1983). The questionnaire comprises 24 statements to which caregivers are asked to answer from five response categories ranging from strongly agree to strongly disagree (see Appendix 8). Answers are scored from 0 to 4, with 4 implying the strongest expression of intimacy. In addition a six-item desirability scale is interspersed throughout the questionnaire. Morris and colleagues' use of the scale with spouse caregivers of dementia sufferer provides the only source of comparative data known to the author (Morris et al, 1988). In that study the questionnaire was administered twice to participants, asking them to rate both their 'current' and 'past' marital intimacy. In this study the questionnaire (MIQ) was administered only at time 1, with participants rating current marital intimacy.



### ***Likert Scales – marital satisfaction and satisfaction with day hospital service***

These are seven point Likert scales with the lower ends of the scales representing greater satisfaction with the marriage and the day hospital service (see Appendix 4). Both scales were devised by the author, the first as an adjunct to the MIQ and the second as the simplest way to quantify caregivers' views of the day hospitals.

The marital satisfaction scale was administered at each time point, the day hospital satisfaction scale was administered only at time 2.

## **2.4 Procedure**

### ***2.4.1 Interview One***

These interviews lasted between 75 and 135 minutes. Once informed consent had been obtained, a semi-structured interview was used to gain qualitative information (see Appendix 9). The categories of information sought were;

Demographic details

Personal health

Details of the partner's illness

Caregiving history

Current provision of formal services

Perceptions of change since partner's illness

Thoughts on the future

Feelings about being a caregiver

Likert scales of optimism, strain and marital satisfaction were administered during this interview, as was the Gilleard Problem Checklist. Questionnaires were administered afterwards in the following order: Pearlin's Subjective Stressors, Significant Others Scale, General Health Questionnaire, Geriatric Depression Screening Scale and Marital Intimacy Questionnaire. This order was used for a combination of practical and clinical reasons. Questionnaires which it was felt would

be difficult for participants to fill out alone were completed first when concentration would be expected to be greater and so that these questionnaires would never be sent away with the participant (Pearlin's Subjective Stressors and the SOS-B). The Marital Intimacy Questionnaire was left until last so that rapport was as well established as possible, and again this questionnaire was never sent away with participants. The same order was used for all participants unless time was limited, in which case the GHQ and the GDSS were given to the participant to take away. This happened on 3 occasions. The researcher followed these people up by sending a letter and stamped addressed envelope after the interview so that there was a 100% return rate.

Apart from these three participants, all scales and questionnaires were administered aurally. This was done in order to maximise the opportunity to build up rapport and to minimise the workload placed on the participants themselves. However it was considered important to ensure that the scales were still administered in a manner consistent with the way they had been designed. Prompt cards were made up showing the possible responses for each questionnaire. These were given to the participant to refer to when deciding on their response to each item read to them by the researcher.

At the end of the interview consent was sought from each participant to approach them for a further appointment. None refused.

A letter was sent to the General Practitioner of each participant informing them of their patients' involvement in the study and enclosing a copy of the consent form.

#### ***2.4.2 Interview Two***

Following the first interview the researcher looked at the day hospital notes of the partners of these 30 participants in order to gain more objective information about illness severity. Attendance lists at the day hospitals were monitored in order to know when partners were discharged. Participants were then approached to ask if they were still willing to participate and if so a further appointment was set up. Once again it was not always possible to arrange these appointments immediately on the partner's discharge. 10 participants were seen a mean of 3.27 (SD=1.94) weeks after

their partners' discharge. The partners of 9 participants had not been discharged when they were seen at time 2, but were nevertheless approached within the originally specified 4-8 week interval.

The second interview took between 20 and 45 minutes and concerned perceptions of change since interview one. Once again the Likert scales were administered during the interview and the questionnaires were administered aurally afterwards in the same order as before (PSS, GHQ and GDSS).

As before, where time allowed, consent was obtained to contact the participant again. At this stage one participant was considered to be experiencing significant mental health problems. Time was taken with this person to help them to consider what options of help were available to them and they were put in touch with a carers' support group. They were also advised to contact their GP and with their permission a letter was sent to the GP summarising their mental health questionnaire scores.

### ***2.4.3 Interview Three***

This meeting was less formal, with no protocol for the interview. All the partners of these participants had been discharged. The main aim was to administer the mental health questionnaires (Likert scales, GHQ and GDSS) and the MIQ.

## **2.5 Analysis of Data**

Data were analysed using SPSS.

Due to the small sample size at time three, no statistical analyses were carried out with these data but trends were examined.

### ***2.5.1 Coding Data from the Interview***

Information about change between time one and time two were coded from the interview. This resulted in categorical data that is used in hypothesis three. Three variables were created;

Change in partner's health

Change in own health

Presence of other adverse life events

Each of these variables has a range of values from -1 (adverse change), through 0 (no change) to +1 (positive change).

### ***2.5.2 Levels of Significance***

Throughout the analysis, one tailed significance tests are used to examine the experimental hypotheses. For all additional and post hoc analyses two tailed significance is used. A significance level of 0.05 is used to determine whether the hypothesis is supported.

### ***2.5.3 Normality of the Data***

In order to determine the appropriateness of using parametric statistics, the data were examined for skewness and kurtosis. Using an alpha level of 0.002, significant skewness was found in the measures shown in table 2.5.3.

		<b>Skewness</b>		<b>Kurtosis</b>	
	<b>n</b>	<b>Statistic</b>	<b>Std Error</b>	<b>Statistic</b>	<b>Std Error</b>
<b>No. Yrs. Carer</b>	30	2.79	0.43	9.63	0.83
<b>GHQ – Somatics 1</b>	30	1.55	0.43	1.62	0.83
<b>GHQ – Depression 1</b>	30	2.31	0.43	4.26	0.83
<b>GPCL – Prob Freq</b>	29	1.64	0.43	3.72	0.85
<b>Disc. Emot Support (Spouse)</b>	24	2.27	0.47	4.63	0.92

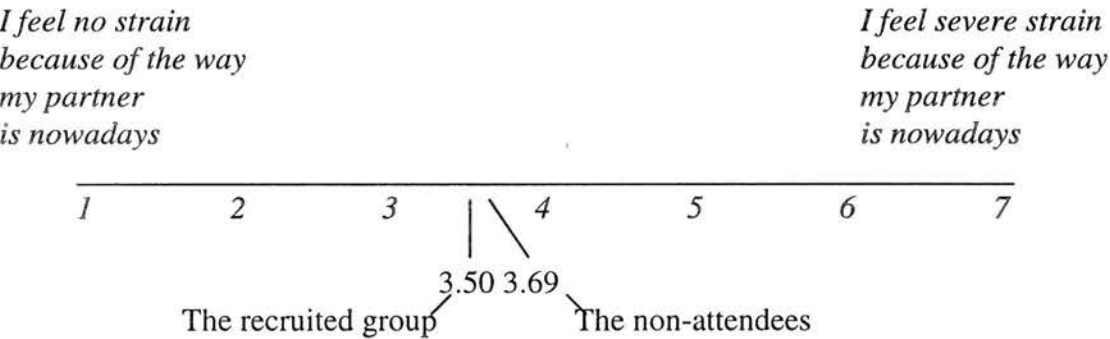
**Table 2.5.3; variables with significant skewness and kurtosis co-efficients**

Of these variables, only the Gilleard Problem Checklist (GPCL) and the discrepancy in emotional support (from the SOS-B) are to be used in the analyses. As the sample size is small, a certain amount of kurtosis and skew is inevitable. It was therefore considered that these co-efficients are small enough to allow treatment of this data as normal.

3. RESULTS

3.1 Comparing the Recruited Group with Non-Attendees

This comparison was carried out between the recruited group and the sample of 16 non-attendees who were followed up by telephone. They were compared on their perception of strain, as measured by the Likert strain scale, and their mean scores are represented diagrammatically below. It can be seen that both groups report strain at around the midpoint of the scale, but slightly towards the not strained end of the scale. Using a two tailed independent samples t test, no significant difference was found ( $t = 0.404$ ,  $df = 44$ ,  $p=0.69$ ).



3.2 Hypothesis One – The Impact of Caregiving

According to the first hypothesis, caregiving will have an impact on mental health and on social and marital relationships. Mean scores on the relevant measures *before* the partners' attendance at the day hospital are used in these analyses.

To test the hypothesis, the mean scores of this sample will be compared with other population means using the independent t test statistic and also one sample t tests where the standard deviations of these comparative populations are unknown. For some of the questionnaires, this sample will be compared with 'cut off' scores for psychiatric caseness.

### 3.2.1 Mental Health

The sample's mean scores on the Geriatric Depression Screening Scale (Mean = 3.03, SD = 2.9) fall below the cut off score of 5. This suggests that overall this sample is not suffering from clinically significant depression. However 26.67% of this sample did have scores indicating significant depression (n=8).

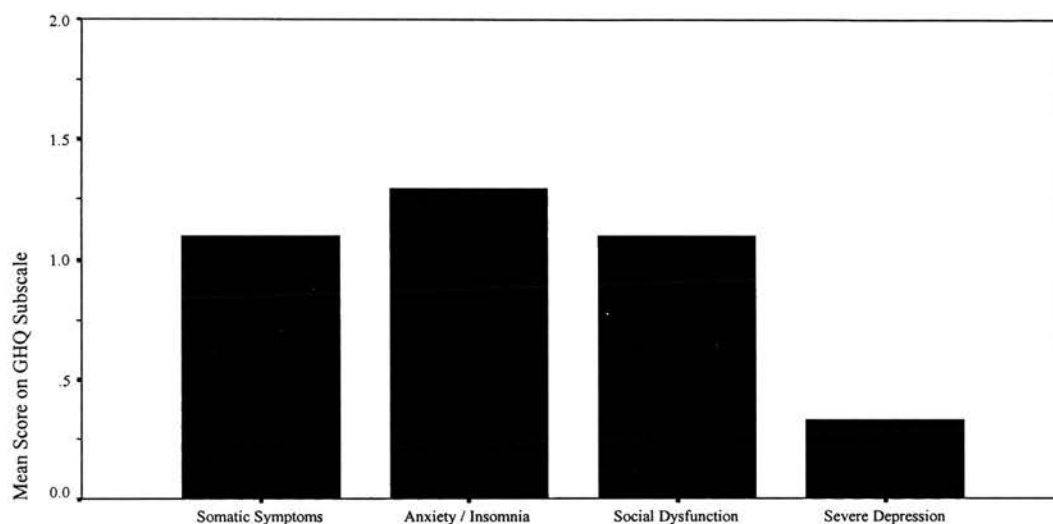
The distribution of scores on the fifteen items of this scale was explored. The five items on which caregivers most frequently scored as 'depressed' were;

<i>Have you dropped many of your activities and interests?</i>	50% YES
<i>Do you feel full of energy?</i>	37% NO
<i>Do you often feel helpless?</i>	27% YES
<i>Do you prefer to stay at home rather than going out and doing new things?</i>	23% YES
<i>Do you think it is wonderful to be alive now?</i>	23% NO

The five items on which caregivers least frequently scored as 'depressed' were;

<i>Are you afraid that something bad is going to happen to you?</i>	10% YES
<i>Are you in good spirits most of the time?</i>	10% NO
<i>Do you feel that your situation is hopeless?</i>	10% YES
<i>Do you feel you have more problems with memory than most?</i>	10% YES
<i>Do you feel pretty worthless the way you are now?</i>	7% YES

The sample's mean scores on the General Health Questionnaire (Mean = 3.83, SD = 3.4) fall below the cut off score of 5. Once again this suggests that overall this sample do not have clinically significant levels of mental health problems. However 36.67% of the sample had scores indicating significant mental health problems (n=11). This proportion includes all those with significant depression. It can be seen from figure 3.2.1 that the greater proportion of symptoms fell into the categories of anxiety and insomnia, somatic symptoms and social dysfunction.



**Figure 3.2.1; the difference in mean scores on the four subscales of the GHQ (n = 30).**

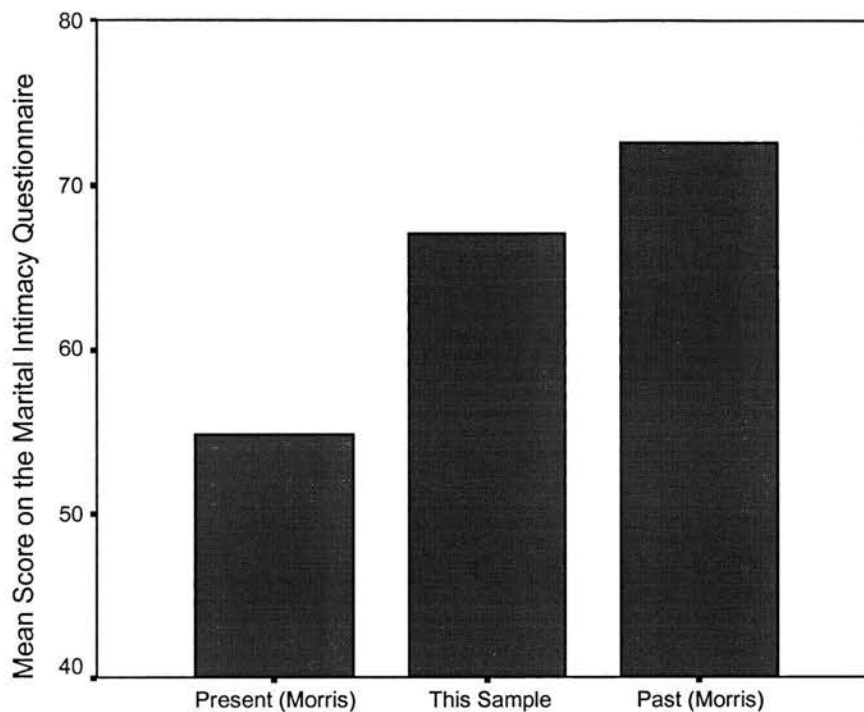
As has been noted above, the sample's mean scores on the Likert strain scale fell slightly towards the less strained end of the scale (Mean = 3.50, SD = 1.4). They were compared with those found in Morris and colleagues' (1988) sample of 20 caregivers for dementia sufferers (Mean = 4.4, SD = 1.4). This sample rated themselves as under significantly less strain ( $t = 2.22$ ,  $df = 48$ ,  $p < 0.05$ ).

This does not therefore provide evidence to suggest that overall these caregivers were experiencing a significant impact on their mental health.

### **3.2.2 Marital Intimacy**

This population's mean scores on the Marital Intimacy Questionnaire (Mean = 67.03, SD = 16.3) were compared with the mean scores of the sample of 20 caregivers for dementia sufferers described earlier (Morris et al, 1988). This population rated significantly higher marital intimacy than the 'current' ratings of Morris's sample ( $t = 2.12$ ,  $df = 48$ ,  $p < 0.05$ ). However, there was no significant difference between this sample's ratings and the 'past' ratings of Morris's sample ( $t = 1.14$ ,  $df = 48$ ,  $p > 0.05$ ). This suggests that there has not been a significant impact on levels of marital intimacy in this sample of caregivers (see Figure 3.2.2).



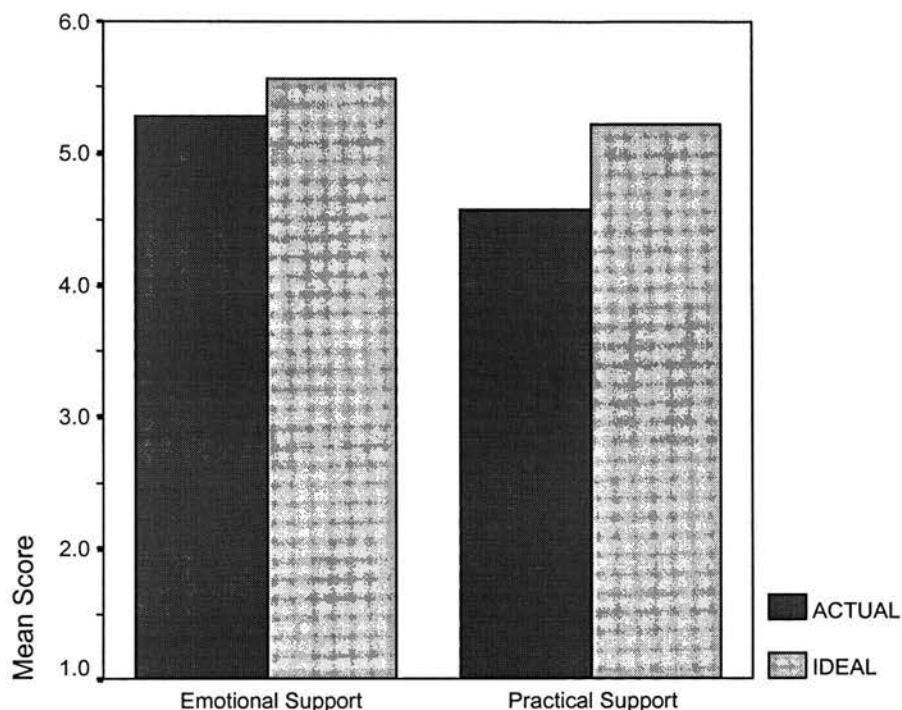


**Figure 3.2.2; this sample's mean MIQ score as compared with past and present MIQ in caregivers for dementia sufferers (Morris et al, 1988).**

The mean social desirability scores on this questionnaire were not significantly different from Morris's sample ( $t = 0.21$ ,  $df = 48$ ,  $p > 0.05$ ).

### ***3.2.3 Social Support***

It can be seen from figure 3.2.3 that ideal levels of emotional and practical social support were higher than actual levels as measured by the SOS-B, suggesting some dissatisfaction with the amount of support received. It can also be seen that both actual and ideal mean perceptions of levels of support were around the 'sometimes' to 'always' (4-6) level of the scale. The discrepancies between actual and ideal levels of both emotional and practical support were found to be significant using a paired  $t$  test ( $t = 4.55$  and  $t = 5.74$  respectively,  $df = 29$ ,  $p < 0.005$ ). This lends some support to the experimental hypothesis.



**Figure 3.2.3; the mean discrepancies between ideal and actual support.**

Some two tailed post hoc analyses of other differences in summary scores of the SOS-B were carried out. The ideal level of emotional support was found to be significantly higher than that for practical support ( $t = 2.33$ ,  $df = 29$ ,  $p < 0.05$ ). However the discrepancy, or dissatisfaction, in practical support was found to be significantly higher than that for emotional support ( $t = 3.92$ ,  $df = 29$ ,  $p < 0.01$ ).

The discrepancy scores were compared with those of a sample of caregivers for Parkinsonian patients (for details see Power et al, 1988). Both emotional and practical discrepancies were found to be significantly lower in this sample ( $t = 9.46$  and  $t = 3.06$  respectively,  $df = 29$ ,  $p < 0.005$ ).

The discrepancy scores for the spouse, for those participants who had rated a spouse ( $n = 24$ ), were compared with spouse ratings for a community sample of 102 elderly people (Lam and Power, 1991) using a one sample  $t$  test. Both samples had discrepancies that indicated some degree of dissatisfaction with the support received. However the discrepancies in both emotional and practical support were significantly higher in this sample ( $t = 1.92$  and  $4.96$  respectively,  $df = 23$ ,  $p < 0.05$ ).

These caregivers therefore rated themselves as receiving significantly less support than ideal. This was less extreme than for carers of Parkinsonian patients, but more extreme than for respondents in a community sample.

### ***3.2.4 Subjective Stressors and Objective Burden***

The Pearlin Subjective Stressor Scale was used in order to look specifically at stressors in the caregiving situation. This sample's mean scores on the scale were compared with the mean scores found in Pearlin's study of caregivers for dementia sufferers (Pearlin et al, 1990) using one sample t tests. With one exception the mean scores of this population fell below the mean scores of Pearlin's sample ( $p > 0.05$ ), indicating less stress in this population. The exception was a significantly greater rating of loss on the item

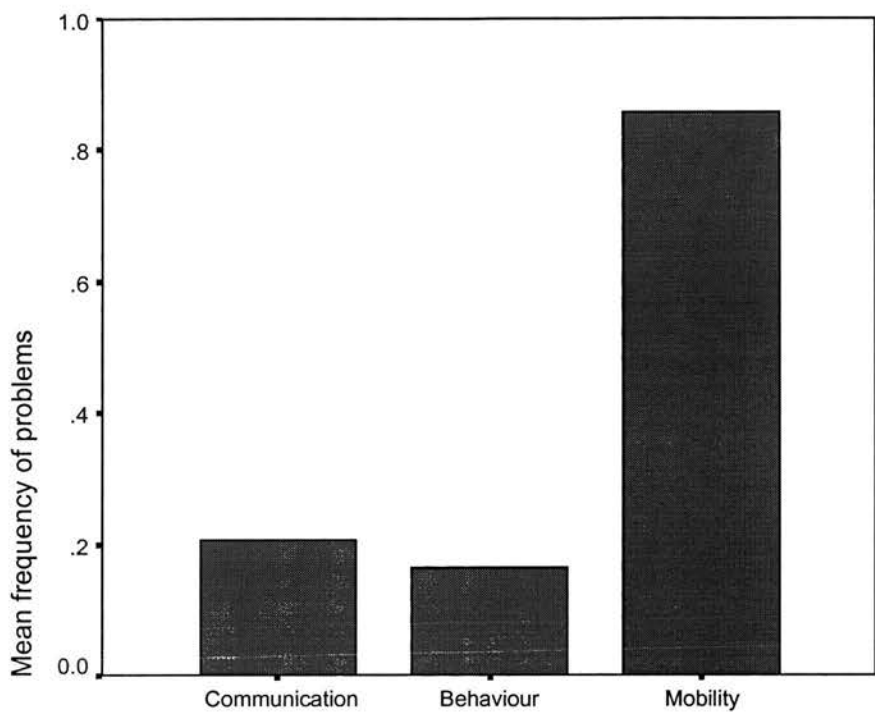
‘The practical things (he / she) used to do for you’

from the Relational Deprivation subscale.

Some measures of the severity of the partners' illness have been given in the previous chapter. A further indication of burden is gained from the Gilleard Problem Checklist. This sample rated the existence of a mean number of 12 (SD = 4.95) problems in their partners. The mean frequency of occurrence of these problems in this sample (Mean = 11.14, SD = 6.09) was significantly lower than that found in Morris and colleague's sample of caregivers for dementia sufferers ( $t = 8.11$ ,  $df = 28$ ,  $p < 0.005$ ).

Gilleard's breakdown of items into subscales of communication problems, behaviour disturbance and mobility problems was used to calculate the mean frequency of occurrence of these problems in this sample. It can be seen from figure 3.2.4 that mobility problems were the most frequently reported by this group. Using two tailed paired sample t tests, it was found that the frequency of mobility problems was significantly greater than both behaviour disturbance ( $t = 6.98$ ,  $df = 28$ ,  $p < 0.001$ ) and communication problems ( $t = 6.70$ ,  $df = 28$ ,  $p < 0.001$ ). There was no difference

between the frequency of behaviour disturbance and communication problems ( $t = 0.76$ ,  $df = 28$ ,  $p=0.453$ ).



**Figure 3.2.4; the distribution of problem types on the Problem Checklist (n=29).**

**3.2.5 Mental Health and Subjective and Objective Burden**

A post hoc analysis of the relationship between measures of mental health and measures of burden was also carried out. This was to explore both the relationship between objective burden and subjective experience as a whole, and the relationship between subjective burden and mental health. Using Pearsons correlations (two tailed) significant relationships were found as shown in table 3.2.5. In particular the frequency of problems in the partners was related to the majority of measures of both subjective burden and mental health. The relationship between subjective burden and mental health was less strong. Although two tailed significance levels are used, these results should be viewed with some caution as multiple analyses have been run.

	<b>GPCL</b>	<b>Freq</b>	<b>PSS</b>	<b>Over</b>	<b>PSS</b>	<b>Capt</b>	<b>PSS</b>	<b>Rel</b>
	<b>of</b>	<b>Probs</b>		<b>load</b>			<b>Depriv</b>	
<b>GDSS</b>	<b>.52</b>	0.004	<b>.43</b>	0.036	<b>.43</b>	0.038	<b>.43</b>	0.036
<b>GHQ</b>	.35	0.064	<b>.62</b>	0.002	.39	0.058	<b>.42</b>	0.040
<b>Strain</b>	<b>.47</b>	0.010	.29	0.166	<b>.51</b>	0.012	.36	0.082
<b>Optimism</b>	<b>.52</b>	0.004	<b>.41</b>	0.046	<b>.45</b>	0.030	<b>.47</b>	0.020
<b>PSS Over</b>	.32	0.128	-	-	-	-	-	-
<b>PSS Capt</b>	<b>.43</b>	0.036	-	-	-	-	-	-
<b>PSS Rel</b>	<b>.70</b>	0.001	-	-	-	-	-	-
<b>Depriv</b>								
<b>n</b>	<b>29</b>		<b>24</b>		<b>24</b>		<b>24</b>	

**Table 3.2.5; the correlations between measures of mental health and strain and measures of stressors.**  
**correlations significant at 0.05 (two tailed) are shown in bold.**

Independent sample t tests were run post hoc in order to explore the characteristics of the subgroup with mental health problems as compared with the rest. No significant differences were found in terms of age, deprivation score, number of years as caregiver or the number of problems and professionals involved at the day hospital ( $p>0.05$ ). However the group comprised proportionately more females (81.82%), more with experience of caregiving in the past (63.64%) and more taking medication themselves (72.73%). With regard to other measures of mental health, the mentally distressed subgroup also had significantly increased levels of strain ( $t = 2.48$ ,  $df = 28$ ,  $p<0.05$ ) but not optimism ( $t = 1.90$ ,  $df = 28$ ,  $p=0.068$ ). With regard to measures of burden, only role overload was significantly raised in this group ( $t = 3.79$ ,  $df = 22$ ,  $p<0.01$ ).

**3.3 Hypothesis Two – The Relationship between Mental Health and Psychosocial Resources**

According to the second hypothesis higher discrepancies between perceived and ideal support and lower levels of marital intimacy will be related to higher levels of mental health symptomatology. This hypothesis was tested principally using Pearson correlations between measures of social support (SOS-B), marital intimacy (MIQ), depression (GDSS), general mental health (GHQ) and the Likert scales. Once again these analyses concern data gathered before the caregivers’ partners had begun attending the day hospitals. The analyses were carried out for the whole group and for the subgroup of nineteen caregivers who were followed up at time two.

**3.3.1 The relationship between social support and mental health**

The correlations between discrepancies in social support and mental health measures are shown in table 3.3.1a.

	Discrep in Emot Support		Discrep in Pract Support	
	r	p	r	p
GHQ	-.20	0.14	-.03	.44
GDSS	-.36	.03	-.01	.48
Likert Strain	.13	.24	.19	.15
Likert Optimism	.22	.13	.13	.24

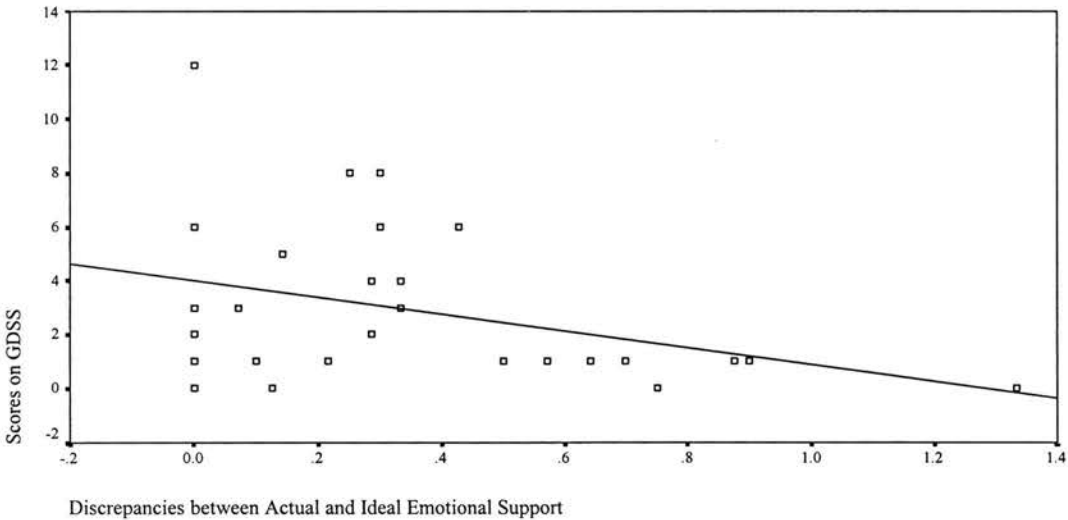
**Table 3.3.1a; Pearson correlations between measures of mental health and discrepancies between actual and ideal support (n=30).**

The correlations between the SOS-B and mental health at time one were also run for the subgroup of nineteen caregivers who were seen again at time two. Similar results were obtained as shown in table 3.3.1b.

	Discrep in Emot Support		Discrep in Pract Support	
	r	p	r	p
<b>GHQ</b>	-.30	0.11	.01	.50
<b>GDSS</b>	<b>-.41</b>	.04	.05	.42
<b>Likert Strain</b>	.13	.29	.25	.15
<b>Likert Optimism</b>	.13	.30	.21	.19

**Table 3.3.1b; Pearson correlations between measures of mental health and discrepancies between actual and ideal support (n=19).**

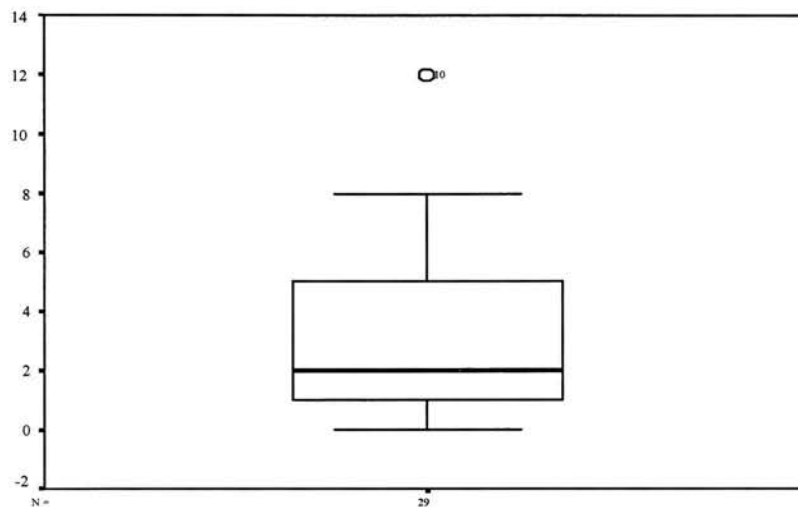
It can be seen that relationships between the discrepancies and the GHQ and GDSS were not in the expected direction. That is, a greater discrepancy in support is related to lower scores on these measures of mental health. Looking first at the discrepancy between actual and ideal practical support, none of the relationships with measures of mental health were found to be significant ( $p>0.05$ ). The discrepancy between actual and ideal emotional support, was again not found to relate significantly to the GHQ and Likert scales. However, scores on the GDSS were found to relate significantly to this discrepancy ( $r = -.36, p<0.05$ ), as is shown in figure 3.3.1a.



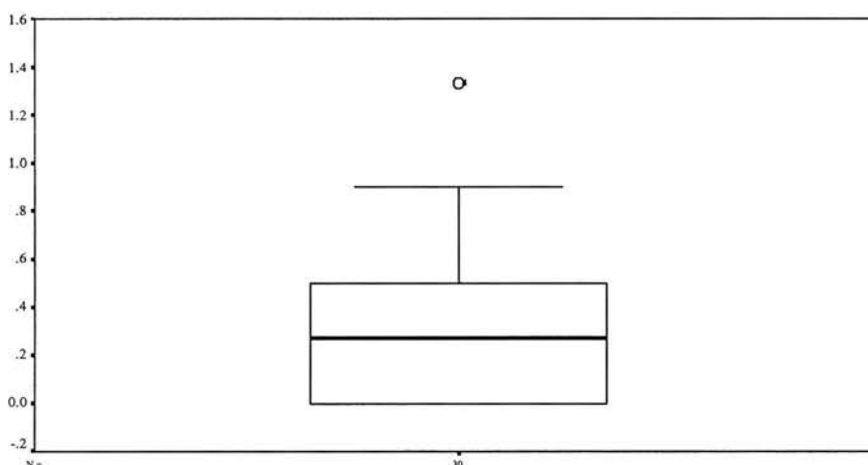
**Figure 3.3.1a; the relationship between depression and the discrepancy in emotional support (n=30).**

This relationship is again not in the expected direction, and the two variables are examined for outliers. Two outliers are identified by examination of box plots of the two variables as shown in figures 3.3.1b and 3.3.1c.





**Figure 3.3.1b; box plot for the geriatric depression screening scale at time one, with one outlier.**



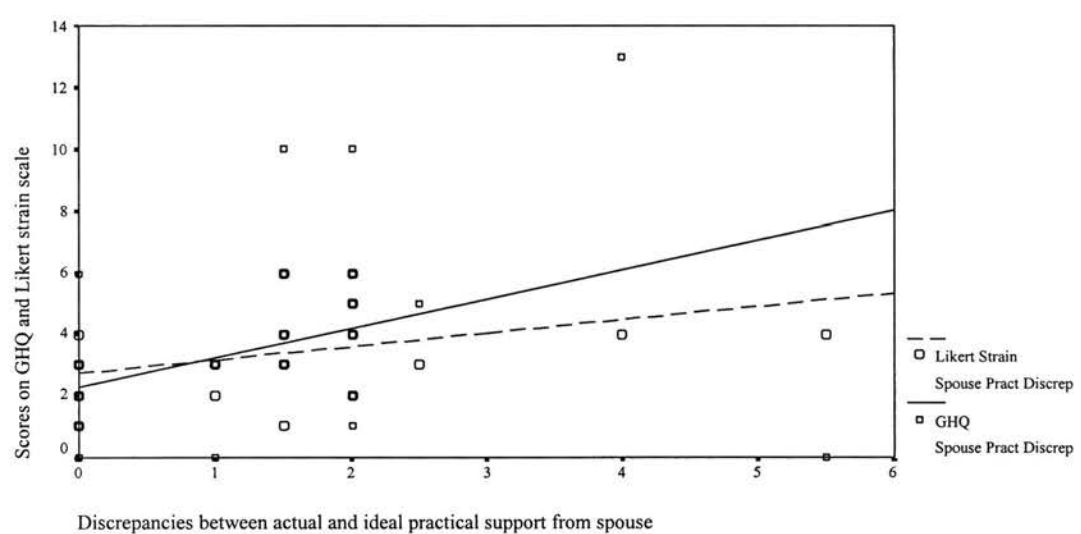
**Figure 3.3.1c; box plot of the discrepancy in emotional support, with one outlier.**

If the outliers identified are excluded from this analysis the relationship ceases to be significant ( $r = -.25$ ,  $p=0.10$ ), though it remains tending towards significance in the direction that was not predicted.

In summary, this data do not provide evidence to support the hypothesis that dissatisfaction with support will be related to mental health. There is some

suggestion that general mental health and depression are paradoxically related to greater satisfaction with support.

A post hoc analysis of the discrepancies only in the provision of support by the spouse was carried out (n=24). A total of eight analyses were run and two were significant. Scores on the GHQ were found to relate significantly to the discrepancy between actual and ideal practical support coming from the spouse ( $r = .37, p<0.05$ , two tailed). Higher levels of mental health symptomatology were associated with greater discrepancies. There was also a significant relationship between perceived strain on the Likert scale and the discrepancy between actual and ideal practical support coming from the spouse ( $r = .40, p<0.05$ , two tailed). This implies greater strain with a greater perceived discrepancy in practical support from the spouse. These correlations are represented in figure 3.3.1d.



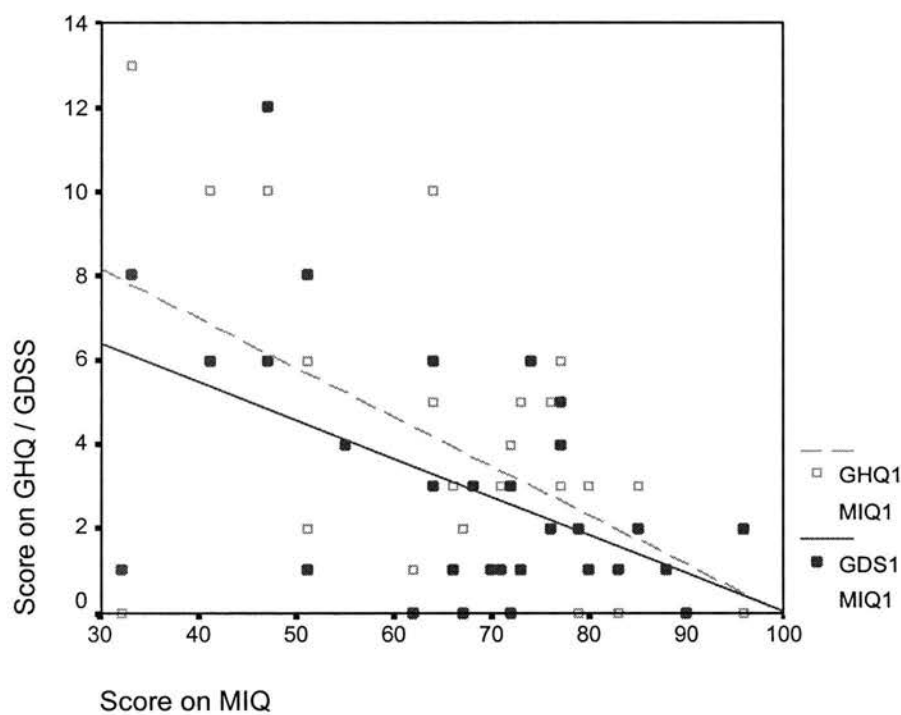
**Figure 3.3.1d; the relationship between the discrepancy of practical support from the spouse and strain and general mental health (n=24).**

Post hoc analyses of the relationships between the actual and ideal scores on the SOS-B and measures of mental health were also carried out. A total of sixteen analyses were run and only two were significant. No significant relationships were found with the GDSS, GHQ or Likert optimism scale. There was a significant relationship between perceived strain and ratings of actual and ideal practical support

( $r = -.39$  and  $r = -.32$  respectively,  $p < 0.05$ , two tailed), implying greater strain with smaller amounts of support.

**3.3.2 The relationship between marital intimacy and mental health**

A significant relationship was found between the MIQ and the GDSS ( $r = -.50$ ,  $p < 0.01$ ) and also between the MIQ and the GHQ ( $r = -.55$ ,  $p < 0.01$ ). In the subgroup of nineteen caregivers significant relationships were also found between the MIQ and the GDSS ( $r = -.59$ ,  $p < 0.01$ ) and between the MIQ and the GHQ ( $r = -.63$ ,  $p < 0.01$ ). This implies greater depressive and other symptoms with decreasing marital intimacy. Figure 3.3.2 shows the relationships in the whole group of caregivers.



**Figure 3.3.2; the relationship between marital intimacy and mental health measures (n=30).**

The Likert strain and optimism scales were also found to relate significantly to MIQ in the whole group ( $r = -.43$  and  $-.44$  respectively,  $p < 0.05$ ) and in the subgroup of

nineteen ( $r = -.55$  and  $-.43$  respectively,  $p < 0.05$ ). Increasing strain and pessimism were associated with decreasing marital intimacy.

The Likert scale of marital satisfaction was found only to relate significantly to the GDSS and the Likert optimism scale, with increasing dissatisfaction related to increasing depression and pessimism (table 3.3.2). It can also be seen from this table that relationships with the other two mental health measures approach significance.

	<b>r</b>	<b>p</b>
<b>GHQ</b>	.304	.051
<b>GDSS</b>	<b>.414</b>	.012
<b>Likert Strain</b>	.300	.054
<b>Likert Optimism</b>	<b>.327</b>	.039

**Table 3.3.2; the correlations between marital satisfaction and measures of mental health (n=30).**

These results imply a significant relationship between certain measures of mental health and measures of marital intimacy and satisfaction in this sample.

### ***3.3.3 The relationship between psychosocial resources and burden***

The relationships between measures of burden and the SOS-B, the MIQ and the Likert marital satisfaction scale were also explored. Forty analyses were run, of which fourteen were significant. Significant relationships were found between measures of the marital relationship and measures of burden, as shown in table 3.3.3.

	<b>Problem (GPCL)</b>	<b>Freq</b>	<b>Role (PSS)</b>	<b>Cap</b>	<b>Role (PSS)</b>	<b>O'load</b>	<b>Rel (PSS)</b>	<b>Dep</b>
	<b>r</b>	<b>p</b>	<b>r</b>	<b>p</b>	<b>r</b>	<b>p</b>	<b>r</b>	<b>p</b>
<b>Marital Intimacy (MIQ)</b>	-.32	0.10	<b>-.65</b>	< 0.01	<b>-.52</b>	0.01	<b>-.60</b>	< 0.01
<b>Marital Sat (Likert)</b>	<b>.47</b>	0.01	<b>.58</b>	< 0.01	.27	0.20	<b>.50</b>	0.01
<b>Spousal Emot Support (Dis)</b>	.37	0.08	<b>.63</b>	< 0.01	.42	0.08	<b>.67</b>	< 0.01
<b>Spousal Pract Support (Dis)</b>	<b>.57</b>	< 0.01	.36	0.14	.41	0.10	<b>.61</b>	< 0.01

**Table 3.3.3; Pearson correlations between measures of the marital relationship and measures of subjective and objective burden (two tailed).**

#### ***3.3.4 Comparing the depressed and non-depressed subgroups***

Independent sample t tests (two tailed) were used to compare the subgroup of mentally distressed participants (n=11) with the majority of participants (n=19) on social support and marital intimacy. Seven analyses were run of which one was significant. As would be expected from the correlations found above, they scored significantly lower on the MIQ ( $t = 2.24$ ,  $df = 28$ ,  $p < 0.05$ ). No significant differences were found on the summary scores of the SOS-B ( $p > 0.05$ ).

### 3.4 Hypothesis Three – Predictors of Change in Mental Health

This hypothesis states that there will be a reduction in rates of depression and stress in the caregiver after their partner has attended the day hospital, controlling for changes in the partner’s illness and other adverse life events. Again controlling for these events, rates of stress and depression will rise following the partner’s discharge from the day hospital. It is hypothesised that these changes will be predicted by the caregivers’ initial perceptions of social support and the marital relationship, as well as by their satisfaction with the day hospital service.

#### 3.4.1 *A description of changes between time one and time two*

The experimental hypothesis assumes that there will be some change in mental health over time. It suggests that other changes between time one and time two will account for this change. Changes measured include changes in the partners’ health, the caregivers’ health and other adverse life events as well as changes associated with the partners’ day hospital attendance. The first three variables were derived from information gathered in the second interview. They are coded variables, but with a direction from adverse change to positive change. The coded variable for adverse life events was in fact excluded from the analysis as only one participant identified the occurrence of a life event in the time between our two meetings. All the variables that measure the events occurring between time one and time two, and which may account for any change in mental health, are described in table 3.4.1.

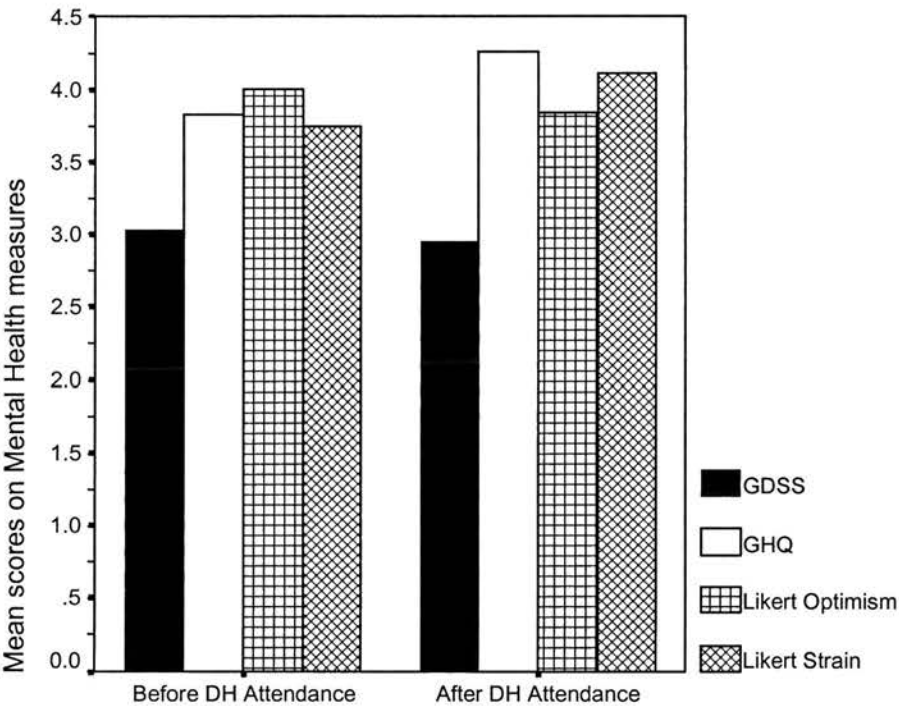
	MEAN	STD DEV	RANGE
<b>No of Day Hospital Sessions</b>	7.37	5.83	1 - 20
<b>No of Professionals involved</b>	2.61	1.23	1 – 6
<b>Satisfaction with the Day Hospital</b>	3.00	1.89	1 – 6
<b>Rated Change in Partner’s Health</b>	-0.16	0.8	-1 - +1
<b>Rated Change in Own Health</b>	-0.26	0.5	-1 - 0

**Table 3.4.1; the variables that may account for any change in mental health between time one and time two.**

It can be seen that satisfaction with the day hospital service approached the middle of the scale, but tended slightly towards the satisfied end. The mean ratings of change in both the partner’s health and the caregiver’s health indicate that overall caregivers reported adverse change and none reported positive change in their own health.

**3.4.2 Changes in Caregiver Mental Health**

It can be seen from figure 3.4.2 that there is no consistent trend towards improved mental health at time two. In fact it is noticeable that scores on the GHQ and the Likert strain scale have increased over this time.



**Figure 3.4.2; the change in measures of mental health after the partners’ attendance at the day hospital (n=19).**

Paired sample t tests were used to examine these changes in measures of mental health. No significant differences were found as can be seen in table 3.4.2a, though it can be seen that the increase in levels of strain approaches significance. Given the



relatively small interval of time between time one and time two, this is perhaps unsurprising.

	Mean (SD) at T1	Mean (SD) at T2	t	p
<b>GDSS</b>	3.05 (3.2)	2.95 (2.8)	0.288	0.389
<b>GHQ</b>	4.00 (3.4)	4.26 (4.2)	0.328	0.373
<b>Strain</b>	3.74 (1.5)	4.11 (1.6)	1.587	0.065
<b>Optimism</b>	4.00 (1.4)	3.84 (1.4)	0.645	0.264

**Table 3.4.2a; t values from the paired sample t tests used to compare measures of mental health at time one and time two (n=19).**

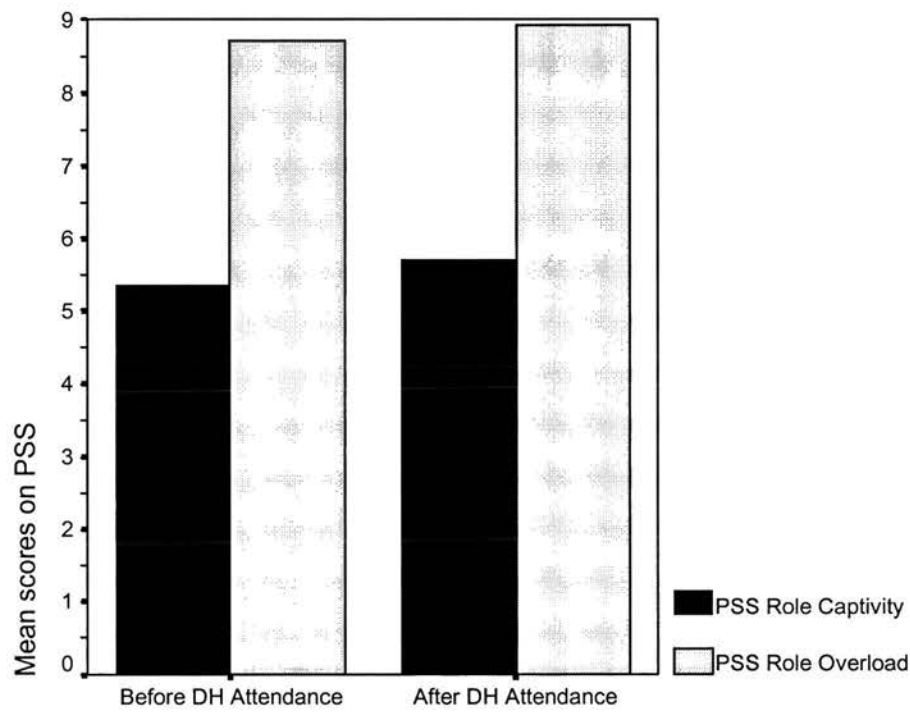
However the lack of change in measures of mental health was explored by post hoc analysis. Since it had been assumed that the day hospital input would have had some effect on caregiver mood, objective variables measuring that input were correlated with mental health at time two. These variables are the number of sessions attended by the partner and the number of professionals involved. A directional component to these variables is assumed and Spearman’s rho correlations used. No significant correlations were found as can be seen in table 3.4.2b, though the correlation between increasing pessimism and fewer day hospital sessions approaches significance. This suggests that, without controlling for other changes, the partner’s day hospital attendance is not contributing to the caregiver’s mood at time two.

	No of DH Sessions		No of Profs Involved	
	rho	p	rho	p
<b>GDSS</b>	-.200	.413	-.245	.378
<b>GHQ</b>	-.162	.507	-.365	.181
<b>Strain</b>	-.368	.121	-.137	.626
<b>Optimism</b>	-.424	.071	-.153	.587

**Table 3.4.2b; Spearman’s rho correlations between measures of mental health at time two and number of day hospital sessions (n=19) and number of professionals (n=15).**

**3.4.3 Change in Subjective Burden**

A post hoc analysis of the change in subjective burden as measured by the PSS was carried out. It can be seen from figure 3.4.3 that there is little change in the measures of overload and captivity after the partners’ attendance at the day hospital. Using paired sample two tailed t tests, no significant difference was found between these measures at time one and time two ( $p>0.05$ ).



**Figure 3.4.3; the change in subjective burden after the partners’ attendance at the day hospital (n=14).**

This therefore provides little evidence to suggest that mental health has improved in these caregivers following their partners’ attendance at the day hospital.

**3.4.4 Changes in Caregiver Mental Health (controlling for other changes)**

General Linear Models (Repeated Measures) were used to control for the effect of the change variables not associated with day hospital attendance, that is changes in the partners’ health and in the caregivers’ health. Within subject analyses were carried

out separately for each of the four repeated measures of mental health with each of the two different types of change as covariates. As no significant changes in mental health measures were actually found this analysis was effectively aimed at discovering whether the ‘change’ variables were masking any effect. The results of these analyses, including the means and adjusted means of the mental health variables, are presented in table 3.4.4.

Effect	Mean T1	Mean T2	F	p
GDSS	3.05	2.95	0.043	.837
GDSS by Change in Partner’s Illness	3.08	2.97	0.101	.755
GDSS	3.05	2.95	0.716	.409
GDSS by Change in Own Health	3.09	2.98	1.353	.261
GHQ	4.00	4.26	0.247	.626
GHQ by Change in Partner’s Illness	4.05	4.23	0.735	.403
GHQ	4.00	4.26	0.000	1.00
GHQ by Change in Own Health	4.06	4.31	0.290	.597
Strain	3.74	4.11	1.976	.178
Strain by Change in Partner’s Illness	3.80	4.12	0.321	.579
Strain	3.74	4.11	0.088	.770
Strain by Change in Own Health	3.76	4.12	<b>5.811</b>	.028
Optimism	4.00	3.84	0.041	.841
Optimism by Change in Partner’s Illness	4.02	3.85	<b>6.040</b>	.025
Optimism	4.00	3.84	0.988	.334
Optimism by Change in Own Health	4.01	3.86	0.752	.398

**Table 3.4.4; F values and significance levels for the change in mental health variables, controlling for other changes (n=19).**

It can be seen that the two indices of change had no significant effect on the difference in GDSS and GHQ at time one and time two.

However, there is a suggestion that perceived change in the caregivers’ health significantly influenced the change in perceptions of strain between time one and time two. Looking at the adjusted means, this implies that the increase in strain

becomes significant when the change in the caregiver's health is controlled for. This is not in the expected direction. Also, perceived change in the partners' health appears to be significantly influencing the change in optimism between time one and time two. Looking at the adjusted means, this implies that the decrease in pessimism becomes significant when the change in the partner's illness is controlled for. These findings should be treated with some caution as the sample size is small and a total of eight analyses were run. It can also be seen that the differences between the adjusted means and the observed means are generally very small.

### **3.4.5 Predictors of Change in Mental Health Measures**

It was hypothesised that initial levels of social support and marital intimacy, as well as satisfaction with the day hospital service, would predict depression at time two. Preliminary Pearson correlations were run in order to see how variables at time one related to mental health at time two (table 3.4.5a).

	GDSS 2		GHQ 2		Strain 2		Opt 2	
	r	p	r	p	r	p	r	p
GDSS1	<b>.87</b>	<0.001	<b>.64</b>	0.002	<b>.47</b>	0.023	<b>.68</b>	<0.001
GHQ1	<b>.71</b>	0.001	<b>.60</b>	0.004	<b>.43</b>	0.033	<b>.51</b>	0.013
Strain1	.26	0.139	.21	0.199	<b>.78</b>	<0.001	<b>.52</b>	0.011
Optimism 1	.34	0.075	.11	0.321	<b>.75</b>	<0.001	<b>.70</b>	<0.001
MIQ	<b>-.53</b>	0.010	<b>-.52</b>	0.010	<b>-.61</b>	0.003	<b>-.63</b>	0.002
D.Em	-.35	0.072	-.18	0.233	.12	0.318	-.11	0.328
D.Pr	.14	0.287	.10	0.337	.14	0.281	.08	0.377
DH Satisfac	.09	0.351	-.02	0.466	<b>.45</b>	0.026	<b>.53</b>	0.009

**Table 3.4.5a; correlations between variables at time one and variable at time two (n=19).**

Unsurprisingly given the lack of change in mental health measures over this time, the greatest correlations are seen between measures of mental health at time one and time two. Marital intimacy also relates strongly to mental health at time two. Satisfaction with the day hospital relates significantly only to the other two Likert scales.

Multiple Regression Analyses were used to discover which variables best predict change in mental health and which variables at time one best predict mental health at

time two. It should be noted that these analyses were performed with rather smaller numbers than is generally required for multiple regression ( $n=19$ ). The results should therefore be treated with some caution. The aim was to discover the direction of causality in correlations already found to be significant, for example the relationship between marital intimacy and mental health. However it should again be noted that given the lack of significant change in mental health measures over time, it must be anticipated that the greatest predictor of mental health at time two is mental health at time one. As there is no conceptual model suggesting an order for the entry of the variables into the equation, variables were entered in the order of the strength of their correlations with the predicted variable.

The regression equation for change in depression is shown in table 3.4.5b.

Predicting Variable GDSS2	Multiple r	Multiple $r^2$	Final Equation Beta	Sig
<b>GDSS1</b>	.867	.753	.649	<b>.002</b>
<b>MIQ</b>	.874	.764	-.260	.123
<b>Disc Em Supp</b>	.880	.774	-.275	.118
<b>Disc Pract Supp</b>	.907	.823	.255	.079
<b>Day Hosp Satis</b>	.909	.826	-.055	.649

**Table 3.4.5b; multiple regression equation for depression at time two.**

It can be seen that the greatest proportion of the variance is predicted by depression at time one. That is the strongest predictor of change in depression is the initial level of depression. The relatively low beta co-efficient for marital intimacy is probably explained by the high correlation between this variable and depression at time one. That is, much of its predictive value is already seen in the predictive value of GDSS1. This will be further explored in later analyses. Measures of social support approach significance if a more lenient alpha level of 0.1 is considered. This was further explored by excluding other less predictive variables from the equation as shown in table 3.4.5c.

Predicting GDSS2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>GDSS1</b>	.867	.753	.838	<.001
	<b>Disc Em Supp</b>	.868	.753	-.057	.727
	<b>Disc Pract Supp</b>	.874	.763	.121	.421

**Table 3.4.5c; multiple regression equation for depression at time two, excluding depression at time one.**

It can be seen that these variables are no longer predicting a significant proportion of the variance. It appears therefore that their relationship with marital intimacy is crucial to their importance in this equation. Change in depression over this short time appears therefore to be principally predicted by initial levels of depression, however some interaction of the relationship variables is predicting a proportion of the variance. This is further explored by excluding GDSS1 from the equation as shown in table 3.4.5d. Satisfaction with the day hospital is also excluded as this variable appears not to be predicting much, if any, of the variance in depression.

Predicting GDSS2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>MIQ</b>	.527	.278	-.650	.001
	<b>Disc Em Supp</b>	.707	.500	-.656	.002
	<b>Disc Pract Supp</b>	.792	.627	.395	.039

**Table 3.4.5d; multiple regression equation for depression at time two.**

This equation suggests that, independently of their relationship to depression at time one, marital intimacy and satisfaction with social support are significantly predictive of depression at time two. Marital intimacy alone predicts 28% of the variance and in combination they explain 63% of the variance in depression. In summary, high marital satisfaction and a low discrepancy in practical support predict low levels of depression. High discrepancies in emotional support also predict low levels of depression. This is counterintuitive and will be discussed further in the final chapter.

These analyses were repeated for the three other mental health variables. The initial equation for the general health questionnaire is shown in table 3.4.5e.

Predicting GHQ2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>GHQ1</b>	.600	.360	.422	.212
	<b>MIQ</b>	.628	.395	-.309	.311
	<b>Disc Em Supp</b>	.634	.402	-.146	.600
	<b>Disc Pract Supp</b>	.653	.426	.166	.490
	<b>Day Hosp Satis</b>	.680	.462	-.204	.366

**Table 3.4.5e; multiple regression equation for general mental health at time two.**

It can be seen that a much smaller percentage of the variance of general mental health is explained by these variables than in the previous equations for depression. None of these variables have a beta co-efficient approaching significance and it therefore appears that the change in general mental health is largely unexplained by this equation. A further equation was set up to examine whether any of the variables predict general mental health independent of any change. This is shown in table 3.4.5f.

Predicting GHQ2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>MIQ</b>	.524	.274	-.578	<b>.017</b>
	<b>Disc Em Supp</b>	.575	.331	-.340	.169
	<b>Disc Pract Supp</b>	.614	.377	.241	.319
	<b>Day Hosp Satis</b>	.625	.391	-.121	.579

**Table 3.4.5f; multiple regression equation for general mental health at time two, excluding general mental health at time one.**

Once the equation is cleared of the relationship between marital intimacy and GHQ at time one, the significance of marital intimacy in predicting general mental health at time two is revealed. Marital intimacy explains 27% of the variance in this equation, but the other variables add little to the equation. In summary, high levels of marital intimacy appear to be the strongest predictor of low levels of general mental health symptomatology.

The initial equation for strain is shown in table 3.4.5g, and once again variables are entered in the order of their correlation with strain at time two.



Predicting Strain 2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>Strain 1</b>	.780	.609	.575	<b>.022</b>
	<b>MIQ</b>	.810	.656	-.266	.194
	<b>Day Hosp Satis</b>	.819	.671	.138	.458
	<b>Disc Pract Supp</b>	.819	.672	-.021	.912
	<b>Disc Em Supp</b>	.819	.672	.008	.966

**Table 3.4.5g; multiple regression equation for strain at time two.**

Here strain at time one is clearly the best predictor of strain at time two, accounting for 61% of the variance. That is, the best predictor of change in strain appears to be initial levels of strain. Marital intimacy adds a little predictive value to the equation, but not significantly so when entered after strain at time one. A further equation was constructed to explore the predictive effects of these variables independently of the change in strain (table 3.4.5h)

Predicting Strain 2	Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
	<b>MIQ</b>	.611	.373	-.541	<b>.015</b>
	<b>Day Hosp Satis</b>	.698	.487	.341	.100
	<b>Disc Pract Supp</b>	.706	.499	.120	.580
	<b>Disc Em Supp</b>	.707	.499	-.024	.911

**Table 3.4.5h; multiple regression equation for strain at time two, excluding strain at time one.**

It can be seen that marital intimacy predicts a significant percentage (37%) of the variance in strain at time two. Satisfaction with the day hospital approaches significance, but social relationships appear to have no predictive effect. In summary, high marital intimacy appears to be the strongest predictor of low levels of strain, though high levels of satisfaction with the day hospital service also tends to predict low levels of strain.

The equation for prediction of optimism at time two is shown in table 3.4.5i.

Predicting Variable Optimism 2	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
Optimism 1	.700	.491	.390	.085
MIQ	.791	.626	-.446	.019
Day Hosp Satis	.809	.654	.225	.255
Disc Em Supp	.839	.704	-.264	.140
Disc Pract Supp	.843	.710	.086	.625

**Table 3.4.5i; multiple regression equation for optimism at time two.**

Here marital intimacy is predicting a significant percentage of the variance in the change in optimism over and above any interaction with optimism at time one. The discrepancy in emotional support also approaches significance at a conservative alpha level. A further equation was run to explore how these variables predict change in optimism (table 3.4.5j)

Predicting Variable Optimism 2	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
Optimism 1	.700	.491	.537	.007
MIQ	.791	.626	-.428	.024
Disc Em Supp	.822	.675	-.251	.162

**Table 3.4.5j; multiple regression equation for optimism at time two.**

Once again, it is optimism at time one and marital intimacy which best predict change in optimism and they account for a total of 63% of the variance. The beta coefficient for discrepancy in emotional support remains non-significant. In summary, initial levels of optimism and marital satisfaction best predict change in optimism. If the effects of these variables are explored independently of optimism at time one, the equation shown in table 3.4.5k is produced.

Predicting Variable	Multiple r	Multiple r <sup>2</sup>	Final Equation Beta	Sig
Optimism 2				
MIQ	.631	.399	-.570	.004
Day Hosp Satis	.755	.569	.432	.021
Disc Em Supp	.782	.611	-.278	.149
Disc Pract Supp	.795	.632	.162	.386

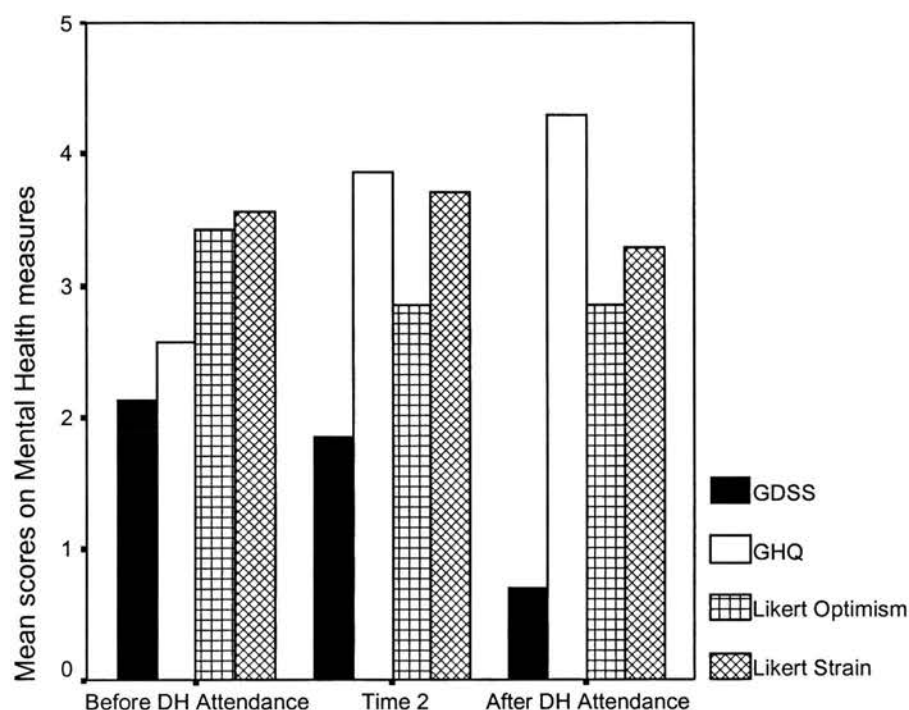
**Table 3.4.5k; multiple regression equation for optimism at time two, excluding optimism at time one.**

Here it can be seen that marital intimacy and satisfaction with the day hospital service best predict optimism. In combination they explain 57% of the variance. The effect of the discrepancy in emotional support remains non-significant. In summary, high levels of marital intimacy and high levels of satisfaction with the day hospital predict high levels of optimism.

### **3.4.6 *Change in Mental Health at Time Three***

As has been noted, the sample size at time three (n=7) is too small for extensive statistical analysis. However it is useful to look at this data as a pilot study for further longitudinal research.

It can be seen from figure 3.4.6 that the degree of depression has declined over the time of the study but that general mental health has worsened. Optimism and strain have fluctuated, but there does not seem to be a trend towards significant overall change.



**Figure 3.4.6; changes in mental health over the study (n=7).**

Independent sample t tests examining the change from time one to time three are shown in table 3.4.6. It can be seen that no significant changes were found ( $p>0.05$ ), but that the decrease in depression approaches significance. It should be noted that the standard deviations are high and the sample size small.

	Mean (SD) at T1	Mean (SD) at T3	t	p
<b>GDSS</b>	2.14 (2.4)	0.71 (0.5)	1.76	0.065
<b>GHQ</b>	2.57 (2.9)	4.29 (5.5)	0.91	0.199
<b>Strain</b>	3.57 (2.2)	3.29 (1.5)	0.51	0.316
<b>Optimism</b>	3.43 (1.8)	2.86 (0.9)	1.00	0.178

**Table 3.4.6; t values from the paired sample t tests used to compare measures of mental health at time one and time three (n=7).**

An analysis of the predictors of these changes was not attempted.

### **3.5 Hypothesis Four – Gender Effects**

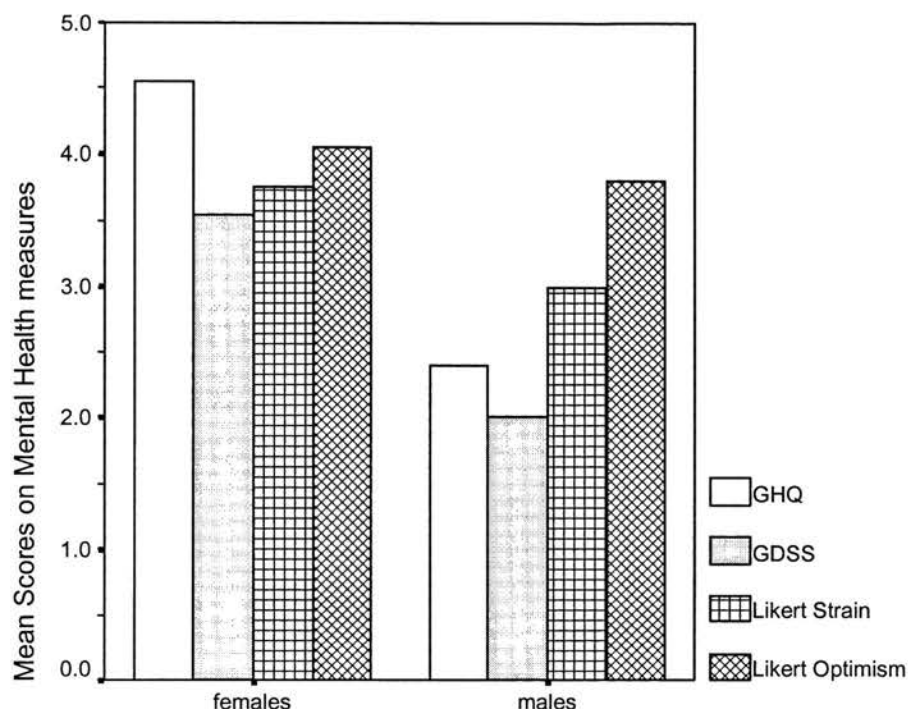
This hypothesis predicts that females will have higher levels of depression and mental health difficulties as well as lower levels of marital intimacy. It also predicts that males will have lower actual and ideal levels of support, smaller discrepancies between the two and a smaller correlation between mood and measures of support and the marital relationship.

#### ***3.5.1 Gender Differences in Demographics and Objective Burden***

Before further analysis was carried out, the two groups were compared in terms of the basic demographics and measures of objective burden that characterised the sample. Using two tailed independent sample t tests the groups were compared in terms of age, deprivation status, number of years as a carer, number of services received and measures of objective burden from both the day hospital notes and the Gilleard Problem Checklist. No significant differences were found ( $p > 0.05$ ). More females (50%) than males (20%) had previous experience of care, but this difference was not found to be significant using a chi squared test ( $\chi^2 = 2.50$ ,  $df = 1$ ,  $p > 0.05$ ). Similar numbers of males (50%) and females (40%) were on medication themselves and again this difference was not found to be significant ( $\chi^2 = 0.27$ ,  $df = 1$ ,  $p > 0.05$ ).

#### ***3.5.2 Gender Differences in Mental Health***

It can be seen from figure 3.5.2 that females tended to have higher scores on the GHQ, the GDSS and on the Likert scales of strain and optimism. This tends to support the hypothesis that the females are more stressed.



**Figure 3.5.2; the differences in scores on the measures of mental health between females (n=20) and males (n=10).**

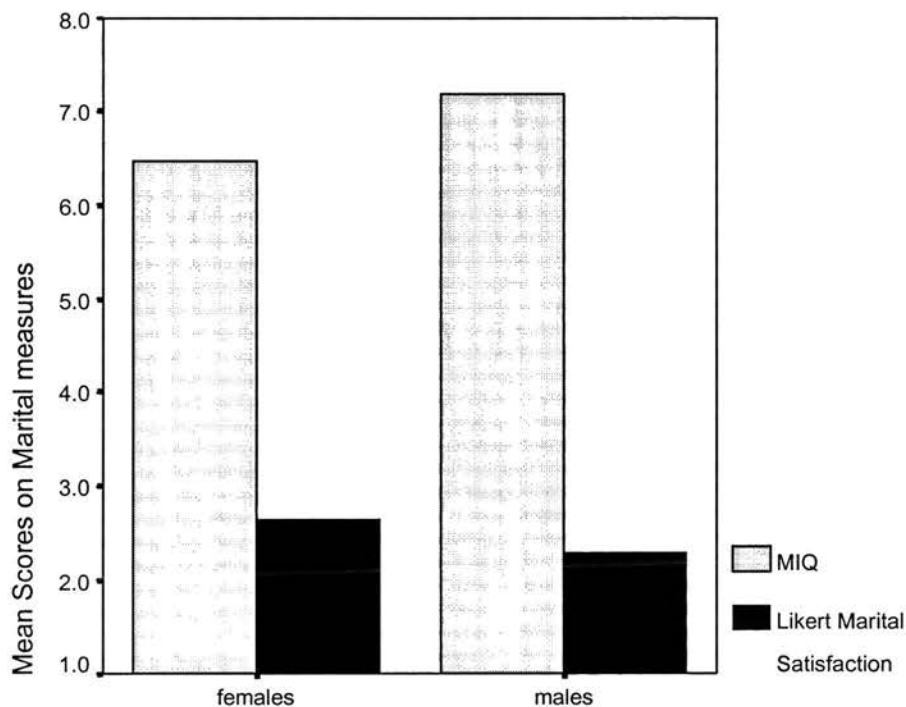
One tailed independent t tests were used to analyse these differences (see table 3.5.2). None of the differences proved to be significant ( $p>0.05$ ), though it can be seen that the gender differences in depression and general mental health problems very nearly approach significance. However this does not provide sufficient evidence to support the hypothesis that females will be more stressed as caregivers.

Test	Gender	Mean (Std Dev)	t	p
GDSS	M	2.00 (1.76)	1.68	0.052
	F	3.55 (3.28)		
GHQ	M	2.40 (2.12)	1.66	0.054
	F	4.55 (3.79)		
Likert Strain	M	3.00 (1.94)	1.14	0.138
	F	3.75 (1.02)		
Likert Optimism	M	3.80 (1.48)	0.48	0.318
	f	4.05 (1.28)		

**Table 3.5.2; the differences in mental health between males and females.**

### 3.5.3 Gender Differences in Marital Intimacy and Satisfaction

It can be seen from figure 3.5.3 that males tended to have higher scores on the MIQ but not on the Likert scale of marital satisfaction. This suggests that the males experience greater marital intimacy, but not necessarily greater satisfaction than the females.



**Figure 3.5.3; the differences in perceptions of the marital relationship between males and females.**

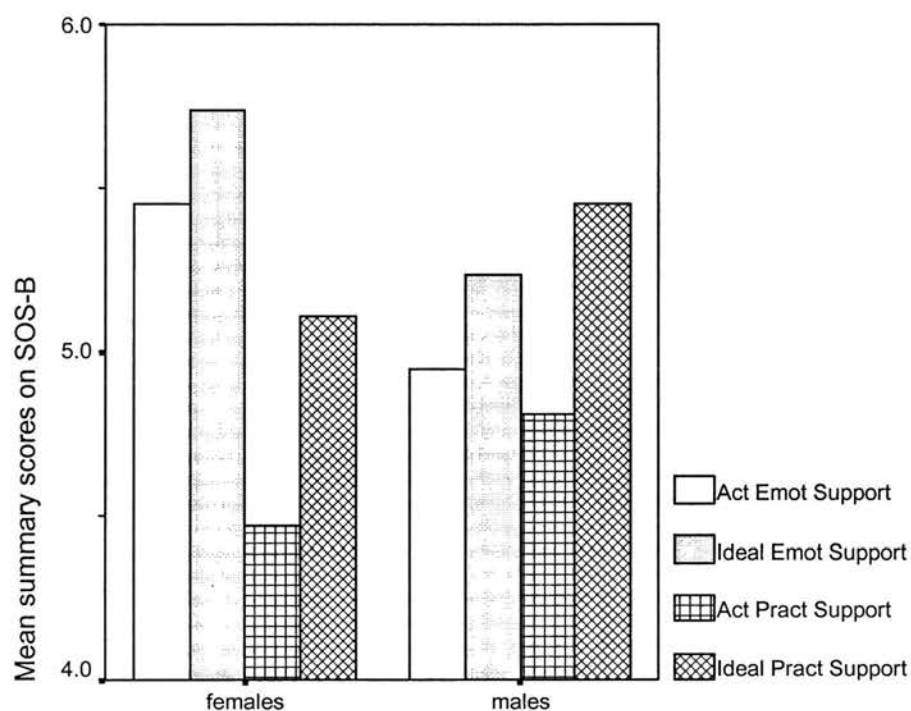
(Mean scores on the MIQ have been divided by 10 in order to present these two variables on the same scale)

However once again these differences did not prove to be significant when tested using one tailed independent t tests for marital intimacy ( $t = 1.16$ ,  $df = 28$ ,  $p > 0.05$ ) and marital satisfaction ( $t = 0.546$ ,  $df = 28$ ,  $p > 0.05$ ). This again does not provide support for the hypothesis that females will experience lower levels of marital intimacy than males.



### 3.5.4 Gender Differences in Social Support

It can be seen from figure 3.5.4 that males tend to have smaller discrepancies between actual and ideal levels of support, as predicted. However although they also have lower actual and ideal levels of emotional support, they have higher actual and ideal levels of practical support.



**Figure 3.5.4; there is greater actual and ideal emotional support in the females, greater actual and ideal practical support in males and greater discrepancies in the females.**

When the groups are compared on the summary measures of the SOS-B, using independent sample t tests, once again the differences are not significant ( $p>0.05$ ). This does not support the hypothesis that males and females will differ in their perceptions of the social support available to them.

### ***3.5.5 Gender Differences in the Relationship between Mental Health and Psychosocial Resources***

In females, significant correlations between marital intimacy and both the GHQ ( $r = -.699, p < 0.001$ ) and the GDSS were found ( $r = -.598, p < 0.005$ ). These correlations are not significant in males ( $r = -.187, p = .605$  and  $r = -.277, p = .438$ , respectively). This suggests that the relationship between decreasing marital intimacy and decreasing mental health holds only for females.

In females, no significant correlations are found between mental health and the summary measures of the SOS-B. In males, optimism was found to correlate significantly with ideal and actual levels of both emotional and practical support as shown in table 3.5.5.

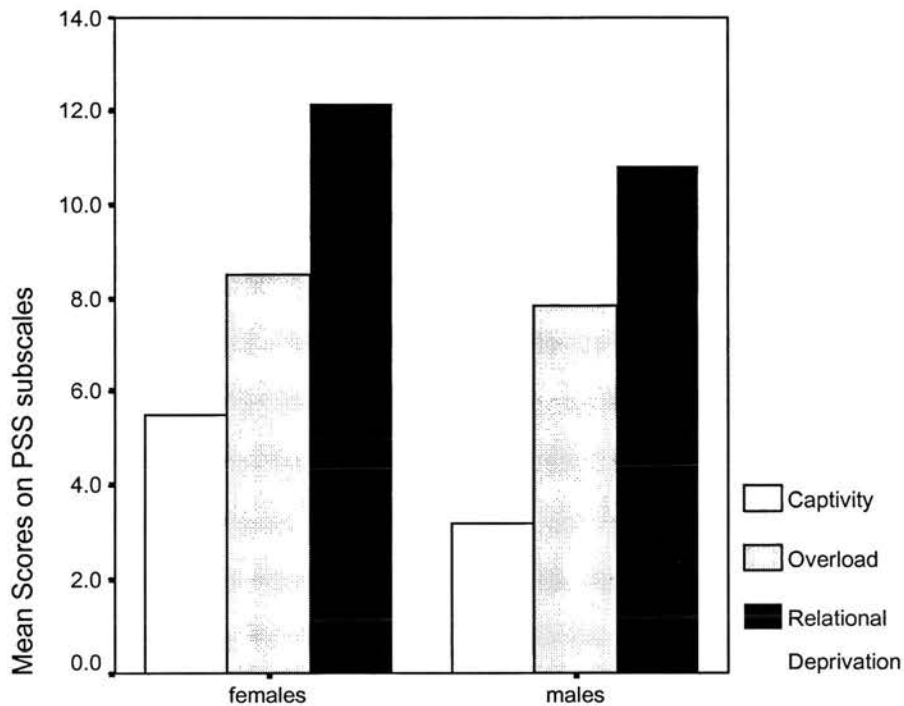
This therefore provides conflicting support for the hypothesis that correlations between measures of mental health and measures of relationships will be stronger for females than males. The hypothesis is supported with regard to marital intimacy but, in terms of informal support, the relationships are stronger for males.

	<b>Females</b>		<b>Males</b>	
	<b>r</b>	<b>p</b>	<b>r</b>	<b>p</b>
<b>Act. Emotional</b>	-.011	0.482	<b>-.675</b>	0.016
<b>Ideal Emotional</b>	.002	0.497	<b>-.673</b>	0.016
<b>Act. Practical</b>	.042	0.430	<b>-.819</b>	0.002
<b>Ideal Practical</b>	-.075	0.377	<b>-.700</b>	0.012

**Table 3.5.5; one tailed Pearson correlations between optimism and measures of social support in males (n=10) and females (n=20).**

### 3.5.6 Gender Differences in Subjective Burden

This was a post hoc analysis of gender differences in perceptions of subjective stressors as measured by the PSS. Females rated themselves higher on measures of role overload, role captivity and relational deprivation as can be seen in figure 3.5.6.



**Figure 3.5.6; gender differences in subjective stressors.**

Using two tailed independent samples t tests these differences were not found to be significant ( $p>0.05$ ), except for significantly greater role captivity in females ( $t = 5.83$ ,  $df = 22$ ,  $p<0.001$ ).

### 3.6 Thematic Analysis of Qualitative Data

The notes made of the caregivers' responses to questions at interview were typed up and reviewed for themes. The identification of themes was guided by the researcher's interpretation and understanding of the caregivers' individual responses and by the literature. This analysis will be presented in sections covering the areas of questions in the interview, with specific reference made as to their relevance to the experimental hypotheses.

Quotes are given to illustrate the themes and the full list of quotes is shown in Appendix 10. The figures in the square brackets represent the participant's randomly allocated number, and also their gender.

#### 3.6.1 The Impact of Caregiving

##### *Changes in their partner*

In response to questions about changes in their partner caregivers spoke of the sadness of seeing their spouse becoming old;

- [2F] He was always larger than life – it's hard for him to adjust*
- [5F] I realise he's an old man and it saddens me*
- [19F] I'm so sorry to see him like that. I'm so sad that so many things have changed for him.*
- [25M] She feels hellish – her quality of life is miserable*

They also spoke of the difficulties of frustration and irritability in their partners;

- [1F] He's shorter tempered and goes off into huffs*
- [9F] He's no a very good patient. He sounds vicious sometimes*
- [15F] He's more irritable – he's not a person for being ill*
- [19F] He's more verbally aggressive to me. He swears at me like he never used to*
- [20F] He's more crabbit and fussy*

and in themselves;

- [2F] I get impatient sometimes*
- [12F] It's kind of off-putting – I haven't the same patience with him*

Many noted the greater dependence in their partners;

[3F] *He was a loner, now he's more clingy*  
[4F] *He's got a little more possessive*  
[6F] *He's fearful, he was never fearful before*  
[9F] *I'm having to mother him*  
[14F] *He was dominant, now I'm dominant.*  
[15F] *I don't molly coddle him – I tell him for his own sake*  
[18F] *He's depending on me, I'd rather have that than have him further away. I'd rather he needed me than I needed him. I'm more of a mother figure than a wife*

and some described the selfishness of illness;

[4F] *He continuously talks about his own ailments*  
[5F] *He's a bit dramatic, he gets me to do things for him he could maybe do*  
[10F] *He's sometimes a bit selfish, like I shouldn't be ill*  
[15F] *He's not got much thought for anyone else – he's interested in himself and that's it*  
[24M] *She's an unusual personality, always looking for others to do things for her*

### ***Changes in their lives***

Whilst many noted the loss of goals and activities;

[6F] *Life is centred round his illness. We've no got any life now*  
[7F] *It's interrupted our plans*  
[8F] *I'm accepting that I will have to give up things*  
[10F] *Well what is there left?*  
[13F] *We've had to shelve some things*  
[21M] *We used to be able to walk out together, and I get much less social time*

others also expressed a philosophical acceptance of the changes and a resolution to adapt;

[1F] *I've had a good life I can't complain*  
[14F] *We've done a lot and we don't have a dull life*  
[13F] *You accept it - I don't expect to be gadding about all over the place anymore*  
[8F] *Physically I'm worn out, mentally I'm adapting myself*  
[16F] *We've done quite well together – we do the best we can*  
[30M] *It's all just the same – once you get to our age .. I'm content – what else could I want?*

### *Changes in the relationship*

A few caregivers noted the change in their roles, one with great pleasure ([14F]) and others with some ambivalence ([5F] and [15F]);

*[3F] I take more decisions, manage more things*

*[5F] I try not take on his roles, but he looks to me to do everything, he used to look after me*

*[14F] I've taken on more roles, like the finances. I've become stronger, I see my own personality again, learning new things – that's a plus. It's given me strength*

*[15F] I can't talk things round with anyone anymore – I make the decisions on my own*

*[26M] I do things I didn't do before*

*[30M] We live our lives much the same as ever but I just do more of the work*

When asked specifically about changes in the relationship, many described the changes in terms of loss;

*[5F] The closeness has gone*

*[6F] I feel it's made me harder, I've no got any feelings now. We still love each other, but the way we talk to each other now – it's awful (tears)*

*[10F] Love's flown out of the window. As you get older you see more faults, you're more in each other's company*

*[20F] We dinnae bother about each other now. I just look after him.*

*[29M] She'll not tell me anything, I feel left out.*

some particularly highlighted the loss of the physical relationship;

*[9F] Sex-wise he's no able, he wants to and we cuddle and all the rest but he gets nothing out of it*

*[22M] There's less of a physical relationship now, but that's not a problem*

Others saw changes not necessarily perceived as a loss ([1F]), or sometimes even perceived as a gain ([8F] and [18F]);

*[1F] There's less love now, more respect*

*[7F] It's mebbe made us a wee bit closer. I feel so sorry for him*

*[8F] he's more considerate, not wanting to be a burden. I think I'm being a bit more considerate too.*

*[14F] There's been a shift – we're both individuals in our marriage*

*[18F] We're more close, better at giving each other space. More like a brother and sister, more comfortable.*

*[26M] We maybe don't argue quite so much and she's maybe a bit more jovial*

Still others said that they saw no real changes ([16F] and [25M]). Some of them described longstanding positive aspects to the relationship ([23M]), others described longstanding difficulties or old losses ([24M] and [27M]);

*[12F] We've never been ... the children came first*

*[16F] He's still the man I married*

*[17F] There's no change really. We've slept separately for years.*

*[23M] We've always been very compatible*

*[24M] We've been estranged since the 1970's. She used to be colourful, now it's a nastier kind of thing. If I'd known then what I know now, I'd never have married her*

*[25M] One's really got to make up one's mind it shouldn't affect one's marriage*

*[27M] There's only one thing wrong and that's the physical side – we lost it a long time ago – it was my fault and I couldn't tell her (tears)*

### **Summary**

These caregivers describe the difficulties of caregiving in terms of the impatience and irritability, the selfishness and demands and the dependence that tend to come with chronic illness. However, many also describe their sorrow and pity for their partner. Despite losses of plans and activities, a sizeable number also speak philosophically about these losses and changes. This would tend to support the finding that the majority of the caregivers in this sample are coping with caregiving without significant impact on their mental health. There was a mixed response to questions about the relationship. Most note changes of some form, though again many see these as positive or at least not detrimental. A few mourn the loss of emotional and physical intimacy and others mourn old losses long pre-dating their current difficulties. Again this tends to provide additional support for the finding that marital intimacy is not greatly compromised in the majority.



### 3.6.2 Coping

When asked about coping, these caregivers described using a variety of strategies including confronting their spouse, escaping in some way or simply ‘getting on with it’.

#### *Confrontation*

[4F] Sometimes I just tell him to stop  
[9F] I shout at him and then he realises  
[10F] I lose the head, shout and bawl. He can't hear me, he's deaf.  
[12F] Perhaps I am unreasonable – I say to him I'm going out, but he doesn't like it

#### *Escape and Distraction*

[5F] Take deep breaths, go out into the garden, listen to music  
[6F] I go into a room and shut the door, or I get out of the house.  
[8F] If I feel I can go out, I go for a walk  
[3F] I watch TV, or the radio  
[12F] I sit and bury myself in my books  
[16F] I try and find something to do that's got nothing to do with it all – a wee spell that's all for me  
[28M] I maybe do a wee bit of gardening or clean the car

#### *‘Getting On With It’*

[3F] Why moan – he never moans  
[15F] It's like a job, you've just got to get through the things you have to do  
[16F] I've always been good at making the best  
[25M] One's just got to get on with it. It's a terrific strain, unending

Other strategies included self talk, alcohol, making a joke or the use of routine;

[7F] I talk myself out of it, I try to hide the tears  
[6F] And I'm drinking more.  
[23M] I try to make a joke about it, rather than losing it  
[26M] I like to get up and ready first – there's an order to things

One caregiver mentioned the importance of friends and family in monitoring their stress;

*[11F] Outsiders see it more, my daughter sometimes says 'Mum you need a rest'*

Some did not feel there was any stress to cope with;

*[14F] If he was difficult it would be a different matter, but he's more amiable*

*[27M] I couldn't cope with her being senile*

### **Summary**

Caregivers use a variety of cognitive and behavioural strategies to cope with their stress. These are of course very individual, but two opposing themes of confrontation and distraction emerge. In further research and analysis it would be interesting to see how the use of these two strategies relates to caregiver mental health. Although distraction might be seen as avoiding the problem, equally confrontation might be seen as creating unnecessary stress. An appropriate balance of the two would seem the ideal, but once again analysis of this requires further information and analysis.

### **3.6.3 Why Do It?**

The overwhelming response of these caregivers to questions about the title of 'caregiver' was in terms of a commitment to the contract of marriage. This was even noted by some as being a part of their generations' values ([6F], [12F] and [28M]);

*[5F] It's all part of the relationship. You have to take the good times with the bad times. It isn't a cross to bear, it's just a part of our life*

*[6F] I was brought up to help and to look after your own.*

*[7F] 'For better, for worse'. I'm in a marriage, I would never do it for someone else*

*[11F] It's a duty, part of the marriage*

*[12F] We were brought up to it, no matter how bad things are you never walk out, I believe in the marriage vows*

*[14F] I'm just a housewife, not a caregiver*

*[16F] I see it as a contract I entered when we married - the vows. I'm a wife.*

*[28M] It's a part of marriage,, when I took me vows it was for better or worse. Not like these youngsters*

Others had similar views, though clearly felt the restriction of the vows;

*[21M] You take vows, you gotta live with them. But there's no enjoyment  
[24M] It's part of the game, you take something on and you see it  
through. I took her on, there's no use gurning about it. 'In sickness and  
in health', it's my duty. I wouldn't like myself if I wrote her off – I'm  
doing it for me.*

A minority of caregivers expressed a positive view of their role, with some mention of reciprocity ([22M]);

*[18F] I need it hen, it's what I'm needing. This is how I like it. I'm doing  
it for pleasure, not for duty. It's the happiest time of my life.  
[22M] I've been looked after well, now it's my turn  
[26M] I'm glad I'm able to do it. If I hadn't been as fit it wouldn't have  
been possible  
[27M] I wouldn't want to do anything else – no regrets  
[29M] I do the best I can for her  
[30M] It keeps you fit – keeps you're weight down!*

### **Summary**

This cohort of caregivers tended to see themselves as spouses rather than caregivers. This indeed seems to be 'for better or worse' with some caregivers taking satisfaction in their role and others apparently feeling trapped within their marriage vows. Again the relationship between the holding of these views and mental health would be interesting to explore.

### **3.6.4 Views on Formal Services and Informal Help**

With regard to the formal services being received by the caregivers aside from the day hospital, there were considerable complaints. This was particularly in relation to 'home helps';

*[4F] I feel he could have had more help  
[5F] It would help if the GP were to pop in like they used to,  
psychologically it would help – to give you a boost  
[21M] The doctors don't help, last time she fell she should have gone  
into hospital and I'd have had a break. Next time I'll call 999  
[17F] They don't do anything, but he likes to see them*

*[17F] Home helps these days are no help*  
*[18F] A home help is no good to me*  
*[25M] There's a limit to what they can help with, they won't cook or clean, you just have to do that when you get back*

The difficulties of receiving help were highlighted by many. This was in terms of the lack of privacy;

*[3F] I learn tips and hints from them, but there are some teething troubles – having everyone ploughing in and out all day*  
*[25M] You could have round the clock, but that's so intrusive*  
*[26M] I'm happy with the level of input – it still leaves us two days to ourselves*

and also the difficulties of accepting respite, both for the caregiver and the ill partner;

*[6F] I don't want respite – I went away without him for a weekend and didn't enjoy it (tears)*  
*[12F] He wouldn't go if there was any respite*  
*[22M] Would never think of respite – we've always been together*

Some caregivers felt that they were managing without help, or even that they *should* manage without help;

*[19F] We're not needing any help, they've been very good*  
*[24M] We're alright now, for the moment*  
*[30M] I don't need any help so long as I'm keeping fit*  
*[1F] You get help when you need it – the doctors are 99%. I know the NHS is stretched, I'm not deserving more help*  
*[14F] I don't need it, it's too easy to say 'I need'. It's too easy to look for too much help instead of helping yourself*  
*[24M] Wife gets the GP out too often – it's embarrassing*

There were however some specific instances of unmet need;

*[8F] Help with bathing would be good, and I'm thinking of getting a night sitter*  
*[10F] If there was a place the two of us could go to with some level of care, for holidays*  
*[15F] Financial help would be good and maybe sitters for getting out if he gets worse*  
*[16F] I'm going to get some private help with housework*  
*[21M] Someone else to help my wife, maybe a health visitor*

The family and neighbours were frequently mentioned as good sources of help, though there were examples from caregivers of them not being supportive.

### ***Summary***

The change in services provided by home helps was a source of dissatisfaction for many caregivers. Apart from those with private cleaners there was a sense that the stresses of caregiving were added to by having to maintain other roles such as housekeeping. This suggests that these caregivers are generally feeling overloaded, with a lack of practical support. Many caregivers also recognised the difficulties of accepting help either because of the boundaries it crosses or through a sense of not being deserving.

### **3.6.5 Views on the Day Hospital**

The prospect of the day hospital service was generally met with relief and appreciation of the possibility of some respite;

*[2F] I feel it's quite good – it gives me a break and he's less stressed*  
*[9F] I can always get bits of things done that I can't do when he's here*  
*[13F] It's lifted a load off my mind*  
*[18F] I go out for the day, shopping*  
*[19F] I could meet up with my sister again*  
*[24M] I won't have to be in at lunchtime to feed her.*  
*[27M] I can now disappear – a chance to sneak off*  
*[29M] It leaves me free to go to the bowls*

More specific benefits mentioned included the monitoring capacity of the day hospital;

*[14F] It's quite a relief. If there is anything it would be picked up*  
*[22M] Other will have the responsibility if something goes wrong*

Benefits to their partner were seen in terms of increased opportunity to socialise and in particular to see people worse off than themselves;

*[19F] I hope it might be good for him, seeing more people*  
*[28M] I'm for it – every little helps, it'll give her more confidence*

*[6F] It'll make him get about more and see other people that's ill  
[18F] It's nice to see him going out to see people, and people worse off  
than him*

As with the dilemma of respite, there were some concerns that their partner may not attend;

*[3F] I'm pleased, I want him to attend but I can't depend on him going  
[10F] I'm happy about it. He's not so happy, but he's going!  
[12F] He doesn't want to go and I'll not force him  
[13F] I think it's great, but he doesn't want to go – 'geriatric'*

There were also those who did not feel it was necessary or likely to be useful;

*[4F] It's not really needed – we just wanted a referral to psychology  
[16F] I don't think there's anything they can do to help and I don't feel I  
need a rest  
[25M] I think it's a racket. All they do is sit about. They try, but do they  
succeed?*

### **Summary**

The day hospital was perceived as a potentially positive input by the majority. Its principal functions were seen in terms of respite for the caregiver, social contact for the partner and a monitoring function.

### **3.6.6 Feelings about the Future**

Many caregivers were puzzled by a question about the future. They replied that they lived a day at a time, crossed bridges as they came to them or simply that they didn't think about it.

Some looked ahead with plans;

*[5F] I always look to the future, booking holidays, looking ahead  
[15F] If we went to Glasgow there would be less need for me to look  
after him all the time and I could get out more  
[16F] A fair amount of hope too, I think we could manage a holiday next  
year.  
[27M] I realise we can't stay in the same house much longer, my son is  
building us a Granny flat  
[28M] We've been looking around for a smaller house*

Many were pessimistic when pressed with the question. This may explain their reluctance to consider it;

*[2F] I feel it could happen again tomorrow*  
*[3F] I don't think he'll last very long, he says he's done*  
*[6F] I feel I've not got any future now – I like to see my family getting on. I can only see him getting worse*  
*[7F] I'm not optimistic at all, I know things will get worse*  
*[9F] I keep trying to be optimistic, but it's hard to visualise – the way he is at the moment*  
*[10F] I feel life's going by too quickly and what is there to it now? I'm tied to the house*  
*[13F] I've not got much confidence since he had his collapse, what was it??*  
*[25M] It's pretty dreadful...grim*

Specific worries raised included the thought of having to place their partner in a home;

*[7F] I don't really want to think about it – going into a home – will it happen?*  
*[10F] I would feel guilty if I put him in a home*  
*[25M] I'd hate the thought of putting her in a home.*

as well as concerns about which of them would live longest;

*[12F] I can't see us living so very much longer – which of us will go first?*  
*[16F] I hope I outlive him, he couldn't live independently.*  
*[22M] I suppose I'll be left alone eventually*  
*[28M] What would happen if I kicked the bucket – it's on me mind – what help would be available?*

### **Summary**

There was an overwhelming sense from this group of caregivers that it was best not to think of the future. Thoughts about the future tended to focus on difficult subjects such as the possibility of their partner's on-going physical deterioration, fears about institutionalisation and concerns about death. It is surprising that optimism scores were not lower, though in fact the mean score was close to the middle of the scale and therefore perhaps again reflects a reluctance to think too deeply about the future.



### 3.6.7 Gender Differences

It can be seen that it is predominantly females who note the short temper, demands and self centredness in their partners. This may simply indicate greater tendency to complain to me in the females. This makes some sense in that as I am also female it might have been expected that I would understand their difficulties and therefore that it would be easier to share these complaints with me. However it could indicate a greater level of irritability in the male partners. This could be hypothesised to be due to many things, many of the women themselves suggested it to be due to a poorer tolerance of ill health in males.

It was solely females who commented on the increased dependency of their partners. Again this may reflect a better rapport between female participants and myself. However this cohort is likely to have had traditional roles within their marriages. The dependency of the husband is therefore worthy of comment by their wives, whereas for the husbands the wives' dependency is not seen as unusual.

Once again it was principally females who made comments about change, apart from physical, in the relationship. This suggests either that the wives are more tuned in to these changes, or that more changes occur if it is the husband who is ill. This latter explanation has some face validity given the comments made about dependency above. However the greater attention of the women to the relationship also ties in with the greater strength of relationship found between mood and the marital relationship in women.

With regard to coping strategies, only females report using confrontation. This again may be a response to the increased bad temper and demands they report in their husbands. It may also reflect their own impatience with the situation - a reluctance to return to the role of caregiver and nurturer. Both women and men used distraction and escape. The male strategies tended to be to distract themselves, to make a joke, have a routine or more frequently to simply 'get on with it'.

### *Summary*

Even taking account of the greater number of females in the study, it is suggested that it is predominantly females who have noticed changes in their partner and their relationship. This may reflect real difference in the partners and the relationship, it may reflect greater insight into these changes by the women or it may simply reflect a greater openness to me in the women I interviewed.

## **4. DISCUSSION**

### **4.1 Summary of the Main Findings**

The negative impact of caregiving for the physically frail was seen in the significant mental health difficulties found in one third of the sample. Marital intimacy appeared preserved when compared with a sample of caregivers for dementia sufferers. There was also significant dissatisfaction with the provision of formal and informal support, particularly practical support. Caregivers' experience of burden was principally in terms of their partners' mobility problems and a sense of role overload. The mental health of the caregivers was significantly related to burden. Overall, the impact was less significant than the impact of caregiving for the cognitively impaired.

Caregiver mental health was significantly negatively related to marital intimacy but not to social support outside the marriage.

Mental health did not change significantly over the course of this study. The best predictor of change in mental health was therefore, unsurprisingly, the initial level of mental health. Marital intimacy was found to predict a significant percentage of the variance in mental health measures, independent of change. Overall, no significant relationships were found between caregiver mental health and their partners' day hospital attendance, except that it had some predictive value for optimism.

There were no significant gender differences in the impact of caregiving, though female caregivers tended to experience more mental health symptomatology and burden than male caregivers. The relationship between marital intimacy and mental health held only for females and there was a significant relationship between measures of practical support and optimism in males.

### **4.2 Recruitment and Sample Characteristics**

Overall thirty caregivers were interviewed initially from a recruitment pool of seventy-six. Given the commitment required from participants in terms of time and

willingness to discuss difficult issues, this seems a reasonable recruitment rate. Despite the greater distance for outlying day hospitals they did not necessarily have a lower recruitment rate, again giving testament to the willingness of this population to participate fully in research. The small sample of those who did not consent to participate and who were followed up, were no more strained than the caregivers who did participate. Their unwillingness to participate must be put down to other factors and should be borne in mind when considering how representative of the caregiving population this sample is.

General characteristics of the group which seem noteworthy include its gender, health and caregiving history. The fact that it is predominantly female may be due to the greater representation of women in this age group and in the caregiving population in general or again may be due to a self-selection bias. It is interesting that Rose and Bruce (1995) note that wives in heavy care situations are generally less likely to agree to an interview, as this does not appear to be the case here. As might be expected given their age, this group were not all in good health themselves with almost half taking medication of some kind. It should also be noted that this was not a naive group, with almost half the sample having previous experience of caregiving. It was not a new group of caregivers either, with a mean number of more than three years of caregiving for the spouse. It may be anticipated that this group will already have made considerable adaptations to their situation. The fact that they are recruited from the day hospital referral lists however does suggest that they may be negotiating some kind of crisis. The practical difficulties of conducting clinical research meant that there was often some delay in me meeting with participants, so again this crisis may have passed by the time they were seen. The final characteristic to highlight is that of the diagnosis of the partners. The majority had strokes, and Parkinson's disease was also represented. As in Draper and colleagues' study this rather muddies the division between physical and cognitive impairment (Draper et al, 1992).

### **4.3 The Impact of Caregiving**

The first experimental hypothesis that caregiving has an impact on the caregiver's mental health and relationships was only partially supported. Mean scores on measures of mental health fell below the cut-off scores for clinical significance. Marital intimacy levels were significantly higher than those in caregivers for dementia sufferers. This sample had significantly lower levels of objective and subjective burden than caregivers for dementia sufferers, except in terms of the perceived loss of practical support from the spouse. However on a general measure of social support there were significant discrepancies between the actual support received and the support ideally wished for, suggesting dissatisfaction in the support available. In particular there was greater dissatisfaction with the support received from the spouse than in a community based sample. Again though, overall the discrepancies were not so great as those found in other caregiving populations.

Overall these results appear to provide little support for the assertion that caregivers of the physically frail suffer significant difficulties, particularly when compared with caregivers of those with cognitive impairment. This is even despite evidence in the literature that spouse caregivers in particular are vulnerable to poor mental health and low morale (Oliver, 1983). However the general findings above mask some important themes, some of which are highlighted in the qualitative data. In this section I will further discuss these results with regard to the qualitative data and previous research.

#### ***4.3.1 Mental Health***

Although it was found that overall this sample did not have clinically significant levels of symptoms of depression and general mental health problems, a sizeable minority did. Over one third had general mental health symptomatology reaching psychiatric caseness and nearly one third of the sample, a subset of those with general mental health problems, would be classified as at least mildly depressed. With regard to the GHQ, this proportion is above community prevalence rates of 16 – 22% (Goldberg, 1978) and falls towards the lower end of the range (31 – 73%) found

in Gilhooly's review of caregivers of dementia sufferers (Gilhooly, 1994). With regard to depression, this sample fall within the range of 14 – 40% found in Morris and colleagues' review of caregivers for dementia sufferers (Morris et al, 1988b). Tennstedt and colleagues' study of older caregivers for the physically frail provides an ideal comparison group (Tennstedt et al, 1992). They also found depressive symptoms in one third of their sample. Measures of strain in this sample fell significantly below those found in a sample of caregivers of dementia sufferers (Morris et al, 1988a).

However, in keeping with Schultz and colleagues' review, cautions concerning the sample should be made (Schultz et al, 1990). The small size of the sample has already been noted; however it is also important to be aware of biases in the sample. This sample is elderly, largely female and is selected through their access to services. Each of these factors potentially carries a vulnerability to psychiatric morbidity and indeed the subgroup of this sample with significant mental health problems had an even greater proportion of females and of those on medication. This is allowed for to some extent as the comparisons made are with similar samples. However, age is not adequately controlled for and it is therefore difficult to draw conclusions as to whether the prevalence of symptoms is due to increased age or to caregiver strain. Comparison with a community based elderly sample would provide some clarity on this, but no such sample was found. The finding of raised prevalence of depression is more adequately compensated for by the use of a geriatric depression screening scale and more appropriate comparison groups. However it should also be remembered that this is not a naïve or new group of caregivers and that depression occurs despite the adaptations that may already have been made.

Responses to the GHQ suggest that much of the morbidity in this group is in terms of anxiety and insomnia, somatic symptoms and social dysfunction rather than severe depression. This then appears inconsistent with the findings of depression on the GDSS. I am not aware of any studies that compare these two scales directly, but subjectively they measure different sets of depressive symptoms. The GDSS comprises items covering anxiety, mood, social function and feelings of hopelessness and worthlessness. This group of caregivers tended to score highly on items assessing social function, mood and feelings of helplessness, rather than feelings of

worthlessness and hopelessness. The depression subscale of the GHQ assesses severe depression and items principally cover suicidal ideation and feelings of worthlessness and hopelessness. The symptoms covered by the first three subscales of the GHQ and the GDSS therefore appear most appropriate for assessing mental health in this population. The subset of caregivers found to have significant mental health problems appear mainly to be experiencing anxiety and sleep difficulties, somatic problems and disruption to their social activities rather than severe depressive symptomatology. Again, this is in line with Schultz and colleagues' contention that caregiver strain is perhaps more accurately described as normal distress rather than psychiatric illness.

The qualitative data suggested that caregivers were aware of the negative impact of caregiving in terms of changes in their partner, in their relationship and their expectations of the future. However they also described apparently successful adaptation to this impact both through their coping strategies and their attributions. This gain makes sense given that this is not a group of new caregivers. These caregivers seemed to be using strategies of distraction and confrontation that encompass both 'emotion-focused' and 'problem-focused' coping. Distraction does not appear to imply any sense of 'working through' the problem whereas confrontation does. A further study would be required to discover the relative effectiveness of these strategy types. There was also a sense of these caregivers 'getting on with it'. They were reluctant to consider the future, preferring to live day by day and make the best of the situation. In the majority they considered themselves as having chosen the role and as being the best person for the job. This again suggests a lack of severe distress and a sense of struggling on through a difficult situation. Although this sample of caregivers is in touch with services, they have not given up their role. The suggestion by Gilhooly (1984) that caregivers in the community are the 'survivors' would perhaps apply equally to this group.

It may be tentatively concluded that this sample exhibits rates of mental health symptomatology lying somewhere between the general population and caregivers of



those with cognitive impairment. These symptoms tend to reflect anxiety, stress and social isolation rather than severe depression and may even be regarded as a normal response to a stressful situation.

#### ***4.3.2 Marital Intimacy***

This sample was compared with a sample of caregivers for dementia sufferers (Morris et al, 1988a) who had rated their 'current' and 'past' levels of intimacy. This sample was found to have levels of marital intimacy lying between the two, but significantly above 'current' levels in that study. Comparison with the measure of 'current' levels is more appropriate as the instructions for filling in the questionnaire were the same in both studies.

This finding lends support to the view that marital satisfaction stands up relatively well to physical illness (Johnson, 1985). Again though, it should be noted that this is not a group of new caregivers and considerable adaptation has probably already been made. These caregivers were rating themselves as having greater marital intimacy than were caregivers of dementia sufferers. As noted in the introduction, the loss of intimacy between couples hit by dementia has been suggested to be due to the perceived loss of the person with dementia, the so-called 'relational deprivation'. Indeed the caregivers in this sample were not found to suffer such deprivation when compared with caregivers of dementia sufferers and this may relate to their relatively high levels of intimacy. This will be further discussed in a later section. The lack of comparative data with a community based sample leaves it unclear as to whether there has been some degree of impact on the marital relationship in these caregivers. Although the difference was not significant, this sample's ratings were below the 'past' levels of caregivers for dementia sufferers. However, this may be due to idealistic retrospective ratings on the part of the caregivers in that study. In the absence of other studies using this scale, further information about the impact on the marital relationship was gained through the interview.

Thematic analysis of the qualitative data highlighted the increased levels of irritability between partners, the change from love to acceptance and the changes in dependency. These are themes that were also highlighted in the review of the



literature. Cantor (1983) sees irritability as an inevitable response to increased proximity and generally raised stress levels in both partners. The taking on of new roles was mentioned by many caregivers and in particular the increased dependence of the ill partner was commented on. Rolland (1994) warns that this can cross old boundaries and set up skews in the relationship. For many of the women, positive aspects to these changes were seen and this will be further discussed in a later section. For some caregivers the changes were felt to have resulted in a closer relationship, as also noted by Schultz et al (1990). For others a sense of distance had been introduced, though this was not always seen by those who expressed it as a loss. In terms of Hansson and Carpenter's cost-benefit analysis (Hansson and Carpenter, 1994), it may be that the relatively high levels of marital intimacy are providing the enduring benefit that outweighs the losses and changes in the relationship and allows the relationship to survive. The effects of individual differences in 'relational competence' were not explored in this study and no history of the relationship was gathered. However some caregivers did appear to resent the loss of intimacy in their relationship and this has been hypothesised to be due in part to an insecure attachment (Ingebretson and Solem, 1995). Although some of these relationships held old difficulties as well as the newer problem of physical illness, there was no sense of imminent breakdown. This group had strong views on their marital obligations. As in Parker's study, these caregivers appear to have successfully accommodated change within their relationship (Parker, 1993).

Overall, there was no strong evidence to support the hypothesis that there was a significant negative impact on the relationship. Qualitatively, some degree of impact was felt and changes have been accommodated by many of these caregivers. This tends to support the suggestion that high levels of marital intimacy are protective in times of stress (Horowitz and Shindelman, 1983). There was also a strong sense of duty and marital obligation in this sample and this has also been suggested to protect and maintain the relationship.

### ***4.3.3 Social Relationships***

This sample was found to have a significant imbalance between their actual and ideal levels of practical and emotional support. This imbalance was less extreme than for caregivers of Parkinsonian patients. The imbalance between actual and ideal levels of support from the spouse was more extreme than for a community-based sample. Once again, this sample appears to be lying somewhere between a community sample and a sample of caregivers for those with cognitive impairment.

These results suggest that these caregivers are expressing significant dissatisfaction with the levels of support that they are receiving. This is perhaps reflecting the loneliness of being the sole carer and the tendency of caregiving to isolate the caregiver from friends and support (Cantor, 1983). Subjectively, at interview caregivers frequently noted the loss of friends through illness and death. There was a sense that it was not possible to call upon peers for help. This is in contrast to Lam and Power's finding that a community sample of older people were very satisfied with the support they received and in some cases felt that they received more than they needed (Lam and Power, 1991). This suggests that the caregiving situation has had an impact on perceptions of support. It is important to note however that it may be that it is only as the caregiver looks for sources of help that the losses are noticed. This is in keeping with Gallo's suggestion that older people tend to be overly optimistic in their assessment of the help available to them (Gallo, 1990). That is, the caregiving situation may be simply highlighting losses that already existed but had not been recognised.

This sample rated significant discrepancies between the actual and ideal support received by the spouse. This seems inevitable, as the spouse is now predominantly the recipient of support. Lam and Power note that there appear to be greater expectations of support from close family, so that this loss of support from the spouse is seen as all the more significant. Again qualitatively, this sample generally described good support from the rest of their family but often expressed the fear of 'being a burden'.

Post hoc analyses suggested that this sample had significantly higher expectations of emotional than practical support, however there was greater dissatisfaction with the provision of practical support. This is very much in keeping with previous research that has also found a substantial unmet need for instrumental support in spouses (Wenger, 1987). It may be suggested from this that these caregivers are experiencing more practical than emotional difficulties in the caregiving situation.

Overall there is some support for the hypothesis that this sample are not feeling well supported. This may be due to the impact of caregiving or to a sudden realisation of old losses. The sense of a lack of support is not so severe as for other caregiver samples, but there is a particular dissatisfaction with the lack of support from the spouse and a particular dissatisfaction in the amount of practical support received.

#### ***4.3.4 Subjective Stressors and Objective Burden***

This sample were found to have lower frequencies of problem behaviours to contend with and to be experiencing lower levels of subjective burden than caregivers for dementia sufferers. The only exception was in terms of a greater perceived loss of the practical support from the ill spouse. However significant relationships were found between measures of objective burden and subjective experience.

Analysis of the objective burden, in terms of the rate of problems using the Gilleard Problem Checklist, suggested that this group of caregivers had fewer problems to deal with than caregivers of dementia sufferers. This is in contrast to Gilleard's own finding that it is the nature, not the number, of problems that distinguishes the two groups (Gilleard. 1984). Exploration of the nature of the problems in this sample found that mobility problems were significantly more frequent than either communication problems or behaviour disturbance. It is therefore acts of 'omission' which are most frequent in this group and, as stated in the introduction, it may be hoped that the day hospital service would begin to redress some of these problems and so relieve the caregiver's burden.

In terms of subjective burden again there were lower levels of role overload, role captivity and relational deprivation than in caregivers for dementia sufferers. Some of

these issues were raised by caregivers in the interview. In particular role overload was mentioned by caregivers noting that they had taken on new roles in addition to their old roles within the relationship. Captivity and the sense of being trapped were not frequently raised problems, except in those caregivers noting longstanding problems in their marriage. Although many caregivers noted changes in their partners, few described losses in terms of their relations with them. This is consistent with the view that although caregivers express a loss of the person in dementia, this loss is not perceived in caregivers of the physically frail.

It is interesting to explore the significant relationships between burden and strain, though as was noted in the previous chapter these results should be treated with some caution. Objective burden was found to relate positively to both subjective burden and measures of mental health. The relationship between subjective burden and mental health was less strong, though it is interesting to note that relational deprivation related to mental health even despite the fact that most partners were not cognitively impaired. This does not lend support to the view that objective burden is not a key factor in caregiver distress or to Zarit and colleagues' assertion that subjective burden is the main predictor of mental distress (Zarit et al, 1986). Rather, it tends to suggest that in this group of caregivers for the physically frail there is a strong relationship between objective burden and perceptions of strain. Given that the objective burden is principally in terms of acts of omission and that caregivers express a sense of role overload, this lends further support to the idea that the strain in these caregivers is mainly due to practical losses and a need for practical support. It is important to recognise though that this is a correlation and that causality cannot be implied. The relationship may reflect either greater depression in more burdened caregivers or a tendency of depressed caregivers to rate greater frequencies of problems and a greater sense of burden.

These results once again suggest that caregivers for the physically ill experience less burden than those caring for the cognitively impaired. Burden is mainly in terms of mobility problems or acts of omission. Qualitatively, the most significant sense of burden was in terms of role overload. The positive relationships between mental health and burden suggest that strain in caregivers is related to their perceptions of

the situation. However it must once again be noted that causality cannot be implied here.

#### **4.4 The Relationship between Mental Health and Psychosocial Resources**

The second experimental hypothesis that greater dissatisfaction with social support and lower levels of marital intimacy will be related to higher levels of mental health difficulties was again partially supported. Dissatisfaction with social support was not found to be related to mental health and burden, though other perceptions of support were found to be significantly related to these measures. Marital intimacy was found to relate significantly to all measures of mental health and burden. Once again, these findings will be discussed with respect to the literature and the qualitative data.

##### ***4.4.1 Social Relationships***

The significant discrepancy between actual and ideal levels of support was not found to relate either to the burden of caregiving or the caregiver's mental health. In fact there was a non-significant trend towards greater depression and mental health symptomatology with less dissatisfaction. This is contrary to Avison and colleagues' suggestion that support plays a direct role in reducing psychological distress in caregivers (Avison et al, 1993). It is also difficult to explain on theoretical grounds, particularly as the direction of correlation is in the expected direction for other analyses of social support and mental health. Post hoc analyses suggested that actual and ideal levels of practical support overall may be negatively related to strain. Dissatisfaction with levels of practical support from the spouse in particular was found to be related to increased strain and poorer general mental health. Measures of satisfaction with both types of support from the spouse were related to measures of burden. It seems that greater dissatisfaction with spousal practical support relates to a greater degree of objective burden and sense of relational deprivation and that greater dissatisfaction with spousal emotional support relates to a greater sense of role captivity and

relational deprivation. Although such post hoc analyses must be treated with some caution, there does seem to be a trend towards the significance of practical support and the support from the spouse for these caregivers. It has been found that they are significantly more dissatisfied with the provision of practical support, especially from the spouse and especially where there is a high degree of objective burden. It also appears that the provision of practical support is more strongly related to caregiver mental health than other forms of support. There is also a suggestion that it is the support from the spouse that is most related to these caregivers' subjective experience of burden. This will be discussed further below.

Qualitatively, caregivers expressed a great deal of dissatisfaction with the practical help available to them both formally and informally. The help they sought was not sophisticated, many simply feeling the need for extra help about the house. The change in the home help service was especially relevant here, with many caregivers regretting the loss of the help with heavy housework that used to be provided by this service. This again seems to imply that for this group of caregivers it is the objective burden, and the help provided to alleviate it, which are most related to mental health outcomes.

#### ***4.4.2 The Marital Relationship***

Marital intimacy and marital satisfaction were found to relate strongly to measures of mental health and burden. That is, greater marital intimacy was related to lower levels of strain and burden. This is in agreement with Trezise's finding of an inverse relationship between marital intimacy and strain (Trezise, 1986). She hypothesised that greater intimacy led caregivers to care out of affection, rather than duty, and to experience less strain. Once again, it must be remembered that this is a correlation and causality may not be implied. It may be that stronger and more intimate relationships protect the caregiver from strain (Horowitz and Shindelman, 1983). However, as noted before, it may be that less strained caregivers tend to rate their relationships and support as being better than do more strained caregivers. The findings noted above should also be considered here. Caregivers also tended to



experience a greater sense of burden with a greater sense of dissatisfaction with the support from the spouse. This seems to imply that marital intimacy and satisfaction with marital support are similar constructs, though marital intimacy appears high despite significant dissatisfaction with support from the spouse. The high marital intimacy is significantly related to low levels of relational deprivation. This is in keeping with the literature suggesting that caregiving is more stressful where the recipient of care is cognitively impaired (Zarit et al, 1986). It also suggests that intimacy can survive loss of support from the spouse, but not the loss of the sense of the spouse as a familiar person.

Referring again to the qualitative data, these caregivers frequently cited duty as a reason to provide care. The extreme sense of duty and commitment they expressed may be maintaining both the relationship and the caregiver's mental health (Fitting, 1986). The expectation that this cohort might see marriage as an 'immutable institution' (Askham, 1995) was certainly borne out. This is contrary to Trezise's hypothesis and suggests that the view of caregiving as dutiful does not necessarily relate to poorer mental health in this sample. It may be that this group of caregivers was sufficiently happy in their marital relationship that the 'duty' of caregiving was not perceived as burdensome. For some though it was perceived as burdensome and the degree to which the sample is representative must also be considered. This was a voluntary group and perhaps caregivers with poorer relationships would be less willing to participate in the research as described in the information sheet. In terms of practical relevance, these caregivers' expressions of fears about the future also supported the suggestion that spouses are generally reluctant to seek institutional care (Gilhooly et al, 1994). It is not clear from this data whether this sample are 'survivors' in their role because of their relatively good mental health, their good marital relationship or an interaction of the two.

## **4.5 Predictors of Change in Mental Health**

The third hypothesis concerning change in mental health found little support, though some interesting findings were reported. The first part of the hypothesis stated that there would be a change in mental health over time. The only significant changes found over this time period were a significant increase in strain when controlling for the change in caregiver health and a significant increase in optimism when controlling for the change in the partners' health over this time. Mental health again did not seem to change significantly even at the third meeting. The second part of the hypothesis referred to the prediction of change. The best predictors of change in mental health therefore tended to be the initial levels of mental health. If change is not considered, the best predictors of mental health were found to be marital intimacy and satisfaction with social support, though this varied between the different measures of mental health. Satisfaction with the day hospital service was predictive only of optimism. These parts of the hypothesis are discussed below, with a section devoted to the effect of the day hospital.

### ***4.5.1 Changes in Mental Health***

At the second meeting with caregivers the measure of depression had declined and optimism had increased, but not significantly. At the third meeting measures of depression continued to decline and this approached significance, but optimism remained unchanged. The increase in optimism is consistent with the experimental hypothesis, but is in fact contrary to Schultz and colleagues finding of increasing pessimism in the primary support persons of stroke victims (Schultz et al, 1988). The decline in depression is also consistent with the experimental hypothesis and reasons for these declines will be explored further below. Measures of strain and general mental health symptomatology had increased at time two, and the increase in strain approached significance. At time three general mental health symptomatology continued to increase non-significantly but strain had declined, again non-significantly. There was no change in the experience of subjective burden. The



increase in strain and general mental health symptomatology may be explained in two ways. Firstly, it was also found that the caregivers rated adverse change in both their own and their partners' health. Given that it has already been found that burden and strain are significantly related, this may be expected to result in increased strain. Also the adverse change in their own health may particularly explain an increased score on the GHQ as the scale does measure somatic symptoms in the respondent. Secondly, this finding may link in with Trezise's finding that caregiver strain increases with increasing service use because it is already the most stressed caregivers who are in touch with services. It may be that these caregivers were already under more strain than they admitted in my first meeting with them. They may have found it easier to be open with me about the extent of their feelings of strain at the second meeting when they knew me better and when there was more hope that these feelings may be addressed.

The effect of the adverse changes in the health of these caregivers and their partners was explored. They were found to have no significant effect on the changes in mental health, except for strain and optimism. If the adverse change in their own health was controlled for, the increase in strain became significant. This is somewhat counterintuitive and it seems to imply that the increase in strain is independent of this change and is therefore due to other factors, such as those described above. If the adverse change in their partners' health was controlled for, the increase in optimism became significant. This seems to imply that this adverse change is having a negative effect on these caregivers' optimism and that if the effect is removed optimism increases, again due to some other factor. Given the correlation found, the number of day hospital attendances may be contributing to this increase in optimism. Objective measures of day hospital attendance were not related to the slight changes in mental health, though the relationship between the number of day hospital sessions attended by the partners and caregiver optimism approached significance. In general this seems to imply that the partners' attendance at the day hospital is having no effect on caregiver strain, but that it may be related to increased optimism in these caregivers. This would be consistent with Gilleard's finding of a lack of relationship between formal care and stress in caregivers (Gilleard, 1984).

In summary, there is a steady trend towards increasing general mental health symptomatology but declining depression in this sample over this time scale. A slight increase in optimism may be related to the partners' day hospital attendance and a slight increase in strain appears to be independent of the factors considered in this study. Apart from the increase in optimism, the partners' day hospital attendance seems not to be related to caregiver mental health.

#### ***4.5.2 Predicting Mental Health***

Apart from the increase in optimism, the best predictor of change in mental health was the initial level of mental health. As was noted in the previous chapter, this is perhaps inevitable given the short time scale of this study. A time scale involving years and considering the caregiving career would be needed to discover which other factors may contribute to the change in mental health over time. It was found though that the best predictor of the increase in optimism was marital intimacy. This reinforces the importance of marital intimacy as a buffer against stressful events (Brown and Harris, 1978).

These data did allow some exploration of the factors that may predict mental health at any one time point. It was found that low depression was best predicted by a combination of high marital intimacy, satisfaction with practical support and dissatisfaction with emotional support. Low general mental health symptomatology was best predicted by marital intimacy. Low strain was best predicted by marital intimacy, with satisfaction with the day hospital having some predictive effect. Low optimism was best predicted again by high marital intimacy and satisfaction with the day hospital. In general then there is strong support for the hypothesis that high marital intimacy has a direct and causal role in positive mental health. Marital intimacy therefore appears to act both as a buffer against stress, but also has an independent effect in increasing well-being as suggested by Aneshensel and colleagues (1995). This seems to be the combined function suggested by Henderson (1977). The data here provide less support for a role of other supporting relationships in predicting mental health. Satisfaction with practical support had some predictive

value when combined with marital intimacy but it had no independent effect. Satisfaction with emotional support was anomalous and cannot be explained by the theoretical models considered in this thesis. Within the limits of the sample size of this study, it seems that the marital relationship is the most important factor in caregiver mental health. Day hospital satisfaction had some predictive value for optimism and strain, though again it was in combination with the effect of marital intimacy. This suggests that the caregivers' views on the day hospital are contributing to their mental health, though again this should be treated with some caution as its role was only apparent in predicting other Likert measures. It may be that caregivers' responses to these scales tended to be very similar and indeed the mean scores on each of these scales did tend towards the centre.

#### ***4.5.3 The effect of day hospital attendance on mental health***

This question has been partially answered above but this section will serve to integrate these findings with the qualitative data. These caregivers were generally unhappy about formal service provision. They had high hopes for the day hospital, anticipating it would provide respite, social contact for their partners and an assessment or monitoring function. They are in fact here identifying some of the key functions of day hospitals (Gilleard, 1984 and Howard, 1994). They are also a typical group to be accessing a medical day hospital with the majority of their partners suffering from strokes and arthritic disorders (Gilleard, 1984). They also seem to be fairly typical in terms of their access to services outside the day hospital in that they have few other sources of help (Parker, 1993) and many expressed a reluctance to be a burden to the National Health Service (Qureshi and Walker, 1989). It was therefore hoped that the day hospital would be of use to these caregivers in the ways that they had anticipated. The quantitative data seem to deny this, although the caregivers generally expressed a moderate level of satisfaction with the service this does not seem in any way to relate to their experience of burden and strain.

## 4.6 Gender Differences

The fourth experimental hypothesis concerning gender differences in mood and relationships was again only partially supported. No significant differences were found between the groups in terms of the basic demographic variables, objective burden, mental health, marital intimacy or social support. However females did tend to have more prior experience of caregiving. There were also some trends in the direction of the hypothesised differences found. Relationships between mental health and measures of relationships differed significantly between males and females. Only females showed a significant relationship between marital intimacy and mental health and only males showed a significant relationship between social relationships and any measure of mental health. Finally, females rated a significantly greater sense of role overload than males.

### *4.6.1 Gender differences in demographic variables and objective burden*

It has already been noted that this sample of caregivers is predominantly female. This may provide support for the feminist view that women are more often caregivers due to a social pressure to adopt that role. The fact that these women tended to have been caregivers before tends to support this argument. This implies some support for Rose and Bruce's idea that caregiving is seen as natural for women (Rose and Bruce, 1995) and this is perhaps particularly true for this cohort. However it has also been noted that the gender bias in this group may reflect the greater numbers of women in this age group. In this case, it may be regarded as surprising that such high proportions of male caregivers were identified. This would tend to support Fisher's view that marital status is a more important predictor of caregiving (Fisher, 1994). Given his concern that male caregivers have tended to be marginalised in research, this study may help to redress the balance. In terms of objective measures of burden and formal help received, there were no differences between the two groups. This therefore implies that comparisons of their mental health and strain are valid.

#### ***4.6.2 Gender differences in mental health and burden***

In fact no differences were found in these measures, though there was a non-significant trend towards greater mental health problems in the wives. As was noted in the literature review, there has been no clear consensus on this in previous studies. This finding appears to support the view that the burden is experienced equally by husbands and wives. Zarit and colleagues suggest that this equality occurs over time, with the experience of strain gradually reducing for female caregivers and increasing for male caregivers (Zarit et al, 1986). This would tend to be supported by the fact that these caregivers are not new to their role. The experience of strain in husbands and wives is explained in different ways in the literature. Wives have been hypothesised to feel trapped in their role and husbands to mourn the loss of intimate exchange. Neither of these hypotheses find support in this data as no significant differences were found between measures of role captivity and relational deprivation in husbands and wives. In fact there was a non-significant tendency for wives to experience both greater role captivity and greater relational deprivation. The only significant difference in subjective experience was a greater sense of role overload in the wives. The consistent non-significant tendency for wives to experience greater mental health problems, strain and burden tends to suggest that they may indeed experience slightly raised levels of these difficulties. It may simply be that the measure of role overload was the only one that achieved significance in a series of analyses of such trends.

It was also noted in the qualitative data that it was generally the women who discussed changes in their life and their relationship. They noted the negative changes in their partners and the losses in their lives. This may be tied to their slightly greater experience of mental health problems, though once again this is simply noted as a possible relationship and no direction of causality can be implied. It was only the women who tended to cope by confrontation. This does not support Ungerson's view that female caregivers adopt the role passively (Ungerson, 1987). Women also used escape strategies and were prepared to leave their partner for short periods of time if necessary which again goes against previous research suggesting that women can become over-involved in the caregiving role (Gilhooly, 1984). Both

genders reported 'just getting on with the job' and gained some sense of personal competence from it. This again is contrary to previous findings (Ungerson, 1987). Only one caregiver mentioned reciprocity as a reason for caregiving and this was a male caregiver. This provides only limited support for the idea that males more happily adopt a caregiving role as a 'pay back' for past care from their wives. These data were not gathered specifically to explore gender coping and only qualitative data are reported, however there is a suggestion that these women are coping with the caregiving situation. They appear to be using coping strategies and attributions that have been suggested in the literature to belong to a more masculine caregiving role. Overall, these results suggest some support for the hypothesis that women experience greater burden in the caregiving situation, but the difference appears to be slight. The women also appear to be using more 'masculine' practical coping strategies and making positive attributions about their role.

#### ***4.6.3 Gender differences in social relationships***

Other hypothesised differences between male and female caregivers were that females would report greater dissatisfaction with relationships in general and would have higher demands for support. There was indeed a non-significant trend towards females having greater discrepancies between actual and ideal support and males having lower ideals for emotional support. However, there was also a non-significant trend towards males having higher ideals for practical support. It is interesting to compare these rather complex results with other findings noted in the literature review. Looking first at the social support, the greater dissatisfaction with the informal support received by the females may simply be a result of their generally poorer mental health. However, it may also reflect Fitting's (1986) comment that women tend to mourn the socio-emotional losses and Gilhooly's (1984) comment that they tend to struggle with the practical demands of the job. The males and females also tended to have different ideals for support. The females tended to have higher expectations of emotional support, which again fits with the idea that female caregivers might mourn the loss of these supports. The males tended to have higher expectations for practical support and this may link with the suggestion that male



caregivers tend to expect greater help in terms of the tasks of caregiving (Noelker and Bass, 1989). In fact it was also found that the male caregivers did not tend to receive more help from formal services than the females and did not appear to have greater objective burden than females. This perceived need for practical help therefore does not seem to stem from an actual need, relative to the females. It was also interesting to find that the males had strong correlations between these measures of support and their levels of optimism, whereas the females did not. This seems to provide additional support for the hypothesis that practical support is important for male caregivers' mental health. However the caution concerning the direction of causality must again be made. It may simply be that more optimistic males are more likely to report higher levels of practical support.

#### ***4.6.4 Gender differences in the marital relationship***

There was a non-significant trend towards the females experiencing lower levels of marital intimacy. This is in the expected direction and provides some support for the view that males experience greater marital intimacy as a result of caregiving and that females are more sensitive to decreasing marital intimacy (Fitting, 1986). From the qualitative data, it was also noted that females appeared to be noticing more negative changes in their partners. It is also interesting to note that the females reported this lower intimacy in the context of poorer mental health. This again suggests that they are sensitive to lower marital intimacy and this will be discussed further below. To explore this trend more fully it would be necessary to see how intimacy changes over the 'caregiving career' for males and females. It would also be interesting to know more about this scale in other populations, for example it may be that men tend to report lower marital intimacy than women anyway.

In the qualitative data there was also a suggestion that both genders were aware of role reversals in their marriage. It was suggested in the literature review that a certain amount of role reversal may be a normal part of the ageing process (Wilson, 1995). However it was suggested that women would resent returning to the nurturing role. These women certainly noted the increased dependency of their husbands. Although most did not express this as a problem, it may be said that their increased irritability and complaints may have reflected their resentment. Some women, however, appeared to be gaining some satisfaction from this role reversal and the return to the nurturing role was seen as having some advantages in that it gave them more power within their relationship than they had previously had.

Significant correlations were found between mental health and marital intimacy in the females and not in the males. This finding lends significant support to the hypothesis that the presence of an intimate relationship is related to a lower incidence of depression in women (Brown and Harris, 1978). It also suggests that marriage does not in fact relate to mental health in men. Given the findings of the previous hypothesis that marital intimacy significantly predicts depression, this seems to suggest that this again only holds for females. That is, marriage is significant in protecting against depression in female but not in male caregivers. The findings here seem to suggest that mental health problems in male caregivers are predicted by other factors, such as the provision of practical support.

#### **4.7 Methodological Issues**

The findings in this study have been discussed with respect to their relevance to previous research. The main findings are generally consistent with previous research, though there are some that contradict it. Also some findings seem to be counterintuitive or are difficult to explain with reference to theory. It is therefore important to consider the power of this study and the weight that may be given to these results.



This study aimed to redress methodological flaws noted in other studies. A longitudinal design was used to gain some idea of the process of caregiving and to consider the causal relationships between variables. Qualitative data were gathered to increase the relevance of the findings in the study, to explore the complexity of caregivers' thoughts and feelings and to increase its accessibility and interest. Finally an attempt was made to recruit a sample representative of a general population of caregivers for the physically frail. The longitudinal design proved to be of too short a time scale to clarify the changes in the caregiving career. Measures taken over the three time points gave some indication of non-significant trends, but there were also considerable fluctuations in these measures. This is consistent with the idea that the caregiving career is a process with crises and lulls, and this study was only able to capture a small picture of this process. A longer study would be required to take account of the fluctuation and to gain a better idea of the predictors of change in the mental health of caregivers. The qualitative data did provide information to support the quantitative findings and to make clear the relevance of the findings. However the interview was not recorded in full, so that anything more than the thematic analysis presented here was not possible. Analysis of detailed transcripts of the interview would have provided more rigorous support for the statements made about the data. Finally, despite considerable efforts to widen the recruitment field, the sample size in this study was small and is inevitably subject to self selection biases. This was particularly so for the second and third time points, so that findings from the second time point should be treated with a considerable amount of caution and the data from the third time point were not submitted to any real analysis. The recruitment field was wide, with limited inclusion and exclusion criteria, so that this is a fairly heterogeneous sample. This is good in some ways because it provides a better representation of the similarly heterogeneous population of caregivers for the physically frail from which the sample is drawn. However, in conjunction with the small sample size, the degree to which this sample represents the population must be called into some question.

Smyer's metaphor of conducting caregiving research as a process of 'juggling while walking' seems an apt one (Smyer, 1993). That feat has been attempted here but the

study is small scale and has the flaws described above. Results of the study should therefore be treated with some degree of caution.

#### **4.8 Conclusions and Avenues for Future Research**

It can be concluded that there is some negative impact of caregiving for the physically frail in that there are raised levels of mental health symptomatology and there is dissatisfaction with the provision of formal and informal support. This impact appears not to be so great as the impact of caregiving for the cognitively impaired. It can be concluded that the impact of caregiving on mental health is strongly related to marital intimacy and indeed marital intimacy seems to have both a direct and a buffering effect on mental health measures. The role of social support outside the marriage is less clear, though may be more important for male caregivers. It can also be tentatively concluded that practical support is of primary significance to this group of caregivers. Despite this, the day hospital did not seem to play a significant role in changes in mental health over time. Despite reasonable ratings of satisfaction with the day hospital the strain in these caregivers actually increased over time. Although there was some evidence that depression and pessimism did decline over this time, it cannot be concluded that the day hospital had any direct role in mediating the impact of caregiving. There were no significant gender differences in the impact of caregiving, though female caregivers tended to experience more strain than male caregivers. Qualitatively, women were using effective coping strategies that are more usually associated with a male caregiving role. It is concluded that the relationship between marital intimacy and mental health held only for females.

These findings suggest several fruitful avenues for future research. It has already been noted that further research should be longitudinal in order to explore further the caregiving process. The increased insight gained by looking at changes even from time two to time three supports this recommendation. A greater emphasis on qualitative data in future research would increase the insight into the experience of the individual caregiver. The heterogeneity of this population has been noted in this

and many other studies and it is perhaps time to focus on individual and gender differences rather than attempting to identify further similarities in the group. The qualitative data in this study begins to suggest the important differences that may emerge. Coping strategies, views on the provision of formal services and perceptions of changes in the marital relationship were particularly disparate within the group. A piece of research concentrating more explicitly on the impact of physical illness on the marital relationship in the elderly would be particularly interesting. Contrary to my expectations, this group of caregivers were generally not unwilling to share their thoughts on their marriage with me. Older adults appeared very able and willing to participate in this type of qualitative research, so that future studies seem likely to be fruitful.

In concluding this study I would like to highlight the resilience of this group of older adults struggling to fulfil their marriage vows in the context of physical illness in their partners. However it is important to put this study in context by emphasising that this is a small group of service users. Not only is it true that not all older adults need care but also that when they do it is often provided solely through interdependence within the marital relationship (Wenger, 1987). As current cohorts age, with very different attitudes to marriage, it will be particularly important to consider how services can best help couples to negotiate these difficulties. This is particularly so as it appears that current formal services are not addressing caregivers' needs.

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## **APPENDIX 1    The letter of introduction**

### **Appendix 1.1**

Dear X

Dr X has told me that your (partner) has recently been unwell. I am sorry for your trouble and know that this must be a difficult time for you both.

Your doctor may have told you that I am carrying out a research study at the X Hospital. The study I am doing aims to find out more about the needs of people like you who are caring for an ill partner.

I have enclosed some information about the study and hope that you might be interested in taking part. As the sheet says, it will involve meeting with me on three occasions over the next three months and answering some questions.

I would like to offer you an appointment to meet with me at the X Hospital on X at X.

You should come to the Out Patient Department and they will let me know that you have arrived. If this time is not convenient, or you would prefer me to visit you at your home, please ring me on X and I will be happy to arrange another time. If you are interested in the study, we can talk about it then and I will give you some time to think about whether you would like to take part. Please bring the consent form with you unsigned. If you have any questions in the meantime, please feel free to contact me at the address or number above. If you do not wish to take part in the study, you do not need to attend this appointment, but I would be grateful if you would let me know.

Thank you for your help, and I hope to meet you soon.

Yours sincerely

Ishbel Dumughn  
Trainee Clinical Psychologist

## Appendix 1.2

### Research Information Sheet

This study is finding out about the needs of people who care for an ill partner. We know that caring for someone can be stressful and that support helps. This study aims to find out more about the way that relationships with others and day hospitals help caregivers to feel less stressed or unhappy.

If you are interested in helping in the study, you can attend an appointment with myself at the Royal Victoria Hospital or I can visit you at home. For the purposes of the study I will only need to see yourself, and your partner will not be involved. At this appointment I can tell you more about the study and answer any questions you may have. You will have time to think about whether you would like to take part, but there will be no pressure to decide straight away if you don't want to.

If you do decide to take part, I would like to spend some time asking you a few questions about the help you need to give your partner and how you are coping. I will also ask you to fill out some questionnaires. Some of these questionnaires will ask about how you are feeling in yourself. Others will ask you about how supported you feel by your friends and family. This appointment should not take longer than an hour and a half.

After your partner has been attending the day hospital for six weeks, I would like to meet with you again to find out how you are getting on. The appointment will be very similar to the first one. I will want to spend some time asking you a few questions and will ask you to fill out the questionnaires again. I would like to meet with you one further time after this to find out how you are getting on once your partner has been discharged from the day hospital. There will be time for you to ask any questions you may have as a result of taking part in the study.

Your participation is entirely voluntary, and if you decide not to take part it will have no effect on the future care of either your partner or yourself. You will also be free to stop at any time if you are unhappy with any part of the study. If you do decide to take part, I am required to let your GP know and I will do this by writing to him after our first meeting.

Any information that you give me will be treated as strictly confidential and nothing that could identify you will be published in any form. Only the researchers will have access to the answers you have made. Questionnaires will only be kept for the duration of the research (about 6 months) and then will be destroyed. Once the research is completed, I can let you know how to obtain the results if you wish.

If you have any questions now, you can contact me, or an independent advisor. I would really appreciate the time and help that you could give to this study.

For more information, please contact ;  
Ishbel Dumughn

Or for independent advice contact ;  
X

**THANK YOU FOR YOUR HELP**

### Appendix 1.3

#### LOTHIAN RESEARCH ETHICS COMMITTEE STANDARD CONSENT FORM

**TITLE OF THE PROPOSED RESEARCH:**

Mood, marital intimacy and perception of supporting informal and formal relationships in older caregivers of physically frail partners.

**NAME OF INVESTIGATOR:**

Ishbel Dumughn

**ADDRESS:**

Clinical Psychology Department  
Royal Victoria Hospital  
13 Craigleith Road  
Edinburgh  
EH4

**TELEPHONE:**

0131 537 5096

**FURTHER INFORMATION IS AVAILABLE FROM:**

Dr Leo Harding  
Clinical Psychologist  
Department of Psychiatry  
Kennedy Tower  
Royal Edinburgh Hospital  
0131 537 6279

**PROCEDURES INVOLVED:**

Attending three interviews with the investigator  
Completing questionnaires

- **I agree to participate in this study.**
- **I have read this consent form and Research Information Sheet and had the opportunity to ask questions about them.**
- **I agree for notice to be sent to my General Practitioner about my participation in this study.**

- I agree to the provision of any clinically significant information to my General Practitioner.
- I understand that I am under no obligation to take part in this study and that a decision not to participate will not alter the treatment that I or my partner would normally receive.
- I understand that I have the right to withdraw from this study at any stage and that to do so will not affect my own or my partner's treatment.
- I understand that this is non-therapeutic research from which I cannot expect to derive any direct benefit.

**Signature of Participant**

**Name of Participant:**

--

**Signature of Investigator: .....**

**Date: .....**

**Four copies to be made**

**Top copy to be retained by Investigator**

**Second copy to be retained by participant**

**Third copy to be sent to participant's General Practitioner**

**An additional copy to be filed in any relevant hospital case notes**

## **APPENDIX 2   Geriatric Depression Screening Scale – Short Form**

Please answer all the following questions by ringing either 'Yes' or 'No'.

- |    |   |                 |
|----|---|-----------------|
| 1  | Are you basically satisfied with your life?                               | <b>Yes / No</b> |
| 2  | Have you dropped many of your activities and interests?                   | <b>Yes / No</b> |
| 3  | Do you feel that your life is empty?                                      | <b>Yes / No</b> |
| 4  | Do you often get bored?   | <b>Yes / No</b> |
| 5  | Are you in good spirits most of the time?                                 | <b>Yes / No</b> |
| 6  | Are you afraid that something bad is going to happen to you?              | <b>Yes / No</b> |
| 7  | Do you feel happy most of the time?                                       | <b>Yes / No</b> |
| 8  | Do you often feel helpless?   | <b>Yes / No</b> |
| 9  | Do you prefer to stay at home rather than going out and doing new things? | <b>Yes / No</b> |
| 10 | Do you feel you have more problems with memory than most?                 | <b>Yes / No</b> |
| 11 | Do you think it is wonderful to be alive now?                             | <b>Yes / No</b> |
| 12 | Do you feel pretty worthless the way you are now?                         | <b>Yes / No</b> |
| 13 | Do you feel full of energy?   | <b>Yes / No</b> |
| 14 | Do you feel that your situation is hopeless?                              | <b>Yes / No</b> |
| 15 | Do you think that most people are better off than you?                    | <b>Yes / No</b> |

### APPENDIX 3 General Health Questionnaire – 28

We should like to know if you have had any medical complaints, and how your health has been in general **over the past few weeks**. Please answer all the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

#### HAVE YOU RECENTLY :

A1 – been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2 – been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 – been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 – felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 – been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 – been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 – been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1 – lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 – had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 – felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 – been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 – been getting scared or panicky for no reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 – found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 – been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

## HAVE YOU RECENTLY :

C1 – been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2 – been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3 - felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4 – been satisfied with the way you’ve carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5 – felt that you were playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C6 – felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7 – been able to enjoy your normal day to day activities?	More so than usual	Same as usual	Less so than usual	Much less so than usual
D1 – been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2 – felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3 – felt that life isn’t worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4 – thought of the possibility that you might make away with yourself?	Definitely not	I don’t think so	Has crossed my mind	Definitely have
D5 – found at times you couldn’t do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6 – found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7 – found that the idea of taking your own life kept coming into your mind?	Definitely not	I don’t think so	Has crossed my mind	Definitely has



**APPENDIX 4    Likert scales**

**Appendix 4.1**

**How much strain do you feel because of the way your partner is at the moment?**

1	2	3	4	5	6	7
<hr/>						
I feel no strain because of the way my partner is nowadays						I feel severe strain because of the way my partner is nowadays

**Appendix 4.2**

**How optimistic do you feel about the future at the moment?**

1	2	3	4	5	6	7
<hr/>						
I feel very optimistic about the future at the moment						I feel very pessimistic about the future at the moment

**Appendix 4.3**

**How satisfied are you with your marriage nowadays?**

1	2	3	4	5	6	7
<hr/>						
I feel very satisfied with my marriage nowadays						I feel very dissatisfied with my marriage nowadays

**Appendix 4.4**

**How helpful did you find your partner's attendance at the day hospital?**

1	2	3	4	5	6	7
<hr/>						
I found the day hospital very helpful						I found the day hospital very unhelpful

## **APPENDIX 5    Pearlin Subjective Stressors**

### **Overload**

I am going to make some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?

You are exhausted when you go to bed at night.

You have more things to do than you can handle.

You don't have time just for yourself.

You work hard as a caregiver but never seem to make any progress.

4     Completely

3     Quite a bit

2     Somewhat

1     Not at all

### **Relational Deprivation**

Caregivers sometimes feel that they lose important things in life because of their partner's illness. To what extent do you feel that you personally have lost the following?

Being able to confide in your partner.

The person that you really used to know.

Having someone who really knew you well.

The practical things he/she used to do for you.

A chance to do some of the things you planned.

Contact with other people.

4     Completely

3     Quite a bit

2     Somewhat

1     Not at all

### **Role Captivity**

I am going to describe some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving?

Wish you were free to lead your own life.

Feel trapped by your partner's illness.

Wish you could just run away.

4     Very much

3     Somewhat

2     Just a little

1     Not at all

## **APPENDIX 6    Gilleard Problem Checklist**

The person;

1	Needs help with dressing (ie can't dress without help)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
2	Needs help to get in and out of chair (ie can't manage without help)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
3	Needs help to get in and out of bed (ie can't manage without help)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
4	Needs help to wash (ie can't manage without help)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
5	Needs help at mealtimes	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
6	Cannot manage stairs (ie needs help with stairs or has to stay downstairs)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
7	Is not safe if outside the house alone	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
8	Is unable to walk outside the house	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
9	Cannot be left alone even for one hour	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
10	Falls	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
11	Is unsteady on his / her feet	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
12	Is incontinent – wetting	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
13	Is incontinent – soiling	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
14	Shows no concern for personal hygiene	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
15	Is careless about own appearance	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
16	Has vulgar habits (eg spitting, bad table manners etc)	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
17	Is rude to visitors	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
18	Uses bad language	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
19	Is physically aggressive	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>

The person;

20	Has temper outbursts	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
21	Creates personality clashes	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
22	Is noisy, shouts	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
23	Demands attention	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
24	Disrupts your personal social life	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
25	Wanders about the house at night	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
26	Keeps asking questions	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
27	Keeps following you around the house	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
28	Forgets things which have happened	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
29	Seems to be unable to hold a sensible conversation	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
30	Seems to be unable to take part in a family conversation	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
31	Seems to be unable to read newspapers, magazines, etc	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
32	Sits around doing nothing	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
33	Shows no interest in news about friends and relatives	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
34	Seems to be unable to watch and follow TV or radio	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>
35	Seems unable to occupy himself / herself doing useful things	<b>Never</b>	<b>Occasionally</b>	<b>Continuously</b>

# SIGNIFICANT OTHERS SCALE (B)



Name: .....

Date: ..... Record Number: .....

## Instructions

Please list below up to seven people who may be important in the individual's life. Typical relationships include partner, mother, father, child, sibling, close friends, plus keyworker. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how individuals would like things to be if they were exactly as they hoped for. As before, please put a circle around one number between 1 and 7 to show what the rating is.

Person 1 – .....		Never	Sometimes					Always
1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
<b>Person 2 – .....</b>								
1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
<b>Person 3 – .....</b>								
1	a) Can you trust, talk to frankly and share your feelings with this person?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty? ..	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?.....	1	2	3	4	5	6	7
	b) What rating would your ideal be?.....	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION



Person 4 –		Never			Sometimes			Always
1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 5 –		Never			Sometimes			Always
1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 6 –		Never			Sometimes			Always
1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 7 –		Never			Sometimes			Always
1	a) Can you trust, talk to frankly and share your feelings with this person?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

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## APPENDIX 8 MIQ

Please say if you strongly agree, agree, are undecided, disagree or strongly disagree with each of the following statements as they apply to you at present. It is best not to spend too long thinking about your answers. Please circle your answer.

1. the feelings I have for my partner are warm and affectionate	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
2. my partner and I find it difficult to agree when making important decisions	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
3. I am very committed to my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
4. my partner makes unreasonable demands on my spare time	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5. all my partner's habits are good and desirable ones	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
6. I enjoy pleasant conversations with my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
7. I wish my partner was more loving and affectionate to me	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
8. my partner has helped me to feel that I am a worthwhile person	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
9. I am unable to tell my partner in words that I love him / her	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
10. on occasion I have told a small lie to my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
11. my partner is liked and accepted by my relatives	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree



12. I look outside my marriage for things that make my life worthwhile and interesting	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
13. when I am unhappy about some aspect of our relationship I am able to tell my partner about it	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
14. my marriage has 'smothered' my personality	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
15. I sometimes have thoughts and ideas I would not like to tell my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
16. I am happy with the physical relationship in my marriage	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
17. my partner does not understand the way I feel	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
18. my relationship with my partner is the most important and meaningful relationship I have	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
19. I wish my partner would try harder to make our relationship more satisfying for us both	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
20. I have never had an argument with my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
21. my partner confides his / her innermost thoughts and beliefs to me	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

22. I have become angry, upset or irritable because of things that occur in my marriage	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
23. my partner and I enjoy several mutually satisfying outside interests together	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
24. I am unable to say to my partner all that I would like	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
25. I sometimes boast in front of my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
26. my partner and I share views on what is right and proper conduct	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
27. my partner is critical of decisions I make	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
28. my marriage helps me to achieve the goals I have set myself in life	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
29. my marriage suffers from disagreement concerning matters of leisure and recreation	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
30. once in a while I lose my temper and get angry with my partner	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

## **APPENDIX 9 Interview One**

### **Demographic Details,**

GP \_\_\_\_\_

May I ask your age?

What was your occupation? What was your partner's occupation? Are you both now fully retired?

### **Details of the Partner's Illness**

How long has your partner been ill?

### **Caregiving History**

How long have you been looking after your partner?

Have you cared for people in the past in this kind of way?

### **Personal Health**

Are you taking any medication yourself?

Do you need help for yourself? Do you feel adequately looked after?

### **Current provision of Formal Services**

What help do you have from formal services?

Home help

GP

District nurse

Health Visitor

Respite care

OP appointments for partner

Other

Meals on Wheels

Sitter Service

Lunch Club

Day Centre

Sleep Over

Tuck-in

Does that help to make your life easier?

Do you feel there is more that could be done to help you?

### **Perceptions of Change since Partner's Illness**

Do you feel your partner has changed at all since they became ill? In what way?

Has it brought about changes in how you see your partner?

Do you notice any change in their personality?

Or in their ability to remember things and concentrate? Is that due to ageing, or something else?

Has the need to care for your partner brought about changes in you? In what way?

Has there been a change in the relationship with your partner? In what way?

Do you feel satisfied with your marriage (Likert)?

### **Thoughts on the Future**

How optimistic do you feel about the future (Likert)?

How optimistic do you feel about your ability to cope with the future?

Do you have any plans for the future?

In what way have these changed since your partner became ill?

How do you feel about your partner attending the day hospital?

Do you anticipate that this will help you?

### **Feelings about being a Caregiver**

How do you feel about being called a 'caregiver'? Is that how you see yourself?

Do you find it stressful, living with and caring for your partner as they are now (Likert)?

The times when it is stressful – how do you cope?

Do you see positive aspects to being a caregiver, for example some people enjoy feeling needed or are glad of the opportunity to give to their partner?

## **APPENDIX 10 Qualitative Data**

### **HELP**

#### **Level of Satisfaction**

[2F] I feel it should have been caught before it happened

[4F] I feel he could have had more help

[27M] If they could just give us a diagnosis – they're useless, they don't listen to me – I want to be consulted

[5F] It would help if the GP were to pop in like they used to, psychologically it would help – to give you a boost

[21M] The doctors don't help, last time she fell she should have gone into hospital and I'd have had a break. Next time I'll call 999

[17F] They don't do anything, but he likes to see them

[7F] Don't want a home help – no use to me

[17F] HH these days are no help

[18F] A home help is no good to me

[21M] Used to have a HH but stopped them, they were lazy

[23M] Not keen for a HH – better off without

[30M] They offered us a HH but they don't work so well now

[25M] there's a limit to what they can help with, they won't cook or clean, you just have to do that when you get back

[24M] DN greatly impressed with that help, I asked for it, things were getting out of hand and I wasn't able to cope

[26M] All very very good – really helps me to know so many folk are helping

#### **Managing or *Should* Manage**

[6F] No need for anything else now – maybe as time goes on

[9F] not needing

[19F] We're not needing any help, they've been very good

[22M] I don't think I need anymore help at the moment

[24M] We're alright now, for the moment

[30M] I don't need any help so long as I'm keeping fit

[1F] You get help when you need it – the doctors are 99%. I know the NHS is stretched, I'm not deserving more help

[10F] We all feel neglected at times.

[14F] I don't need it, it's too easy to say 'I need'. It's too easy to look for too much help instead of helping yourself

[24M] Wife gets the GP out often – embarrassing

### **Family**

[7F] Good family

[13F] my daughter's very good

[27M] Very supportive family

[16F] I wouldn't want my daughter to give things up to look after him

[28M] At the moment I get help within the family and that's enough

[29M] Her daughter's a born trouble maker – no help

### **Neighbours**

- [3F] The neighbours are good
- [10F] The neighbours are good
- [20F] The neighbours are not so friendly

### **Dilemma of Respite**

- [1F] I would like a good night out and a good night's sleep
- [3F] If someone could come and just sit with him
- [6F] I don't want respite – I went away without him for a weekend and didn't enjoy it (tears)
- [12F] He wouldn't go if there was any respite
- [22M] Would never think of respite – we've always been together

### **Problems of Privacy**

- [1F] We're lucky we don't have to depend on others. I wouldn't have anyone else living here – it would disturb him
- [3F] I learn tips and hints from them, but there are some teething troubles – having everyone ploughing in and out all day
- [25M] You could have round the clock, but that's so intrusive
- [26M] I'm happy with the level of input – it still leaves us two days to ourselves

### **Plans and unmet needs**

- [8F] Help with bathing would be good, and I'm thinking of getting a night sitter
- [10F] If there was a place the two of us could go to with some level of care, for holidays
- [15F] Financial help would be good and maybe sitters for getting out if he gets worse. I would be better supported in Glasgow with the family, but we can't get a house
- [16F] I'm going to get some private help with housework
- [21M] Someone else to help my wife, maybe a health visitor

## **CHANGES**

### **Sadness of Getting Old**

- [1F] He needs so much help, he's old now, I put his needs first
- [2F] he was always larger than life – it's hard for him to adjust
- [5F] I realise he's an old man and it saddens me
- [19F] I'm so sorry to see him like that. I'm so sad that so many things have changed for him.
- [21M] I think she's given up
- [22M] I'm sad to see her as she is
- [25M] She feels hellish – her quality of life is miserable
- [28M] She's slowed down and isn't able to do what she used to do
- [29M] She's older, slower

### **Frustration**

- [1F] He's shorter tempered and goes off into huffs

[4F] He gets frustrated  
[7F] He's more frustrated  
[9F] He's no a very good patient. He sounds vicious sometimes  
[15F] He's more irritable – he's not a person for being ill  
[19F] He's more verbally aggressive to me. He swears at me like he never used to  
[20F] He's more crabbit and fussy  
[30M] She gets a bit fed up – it's only natural at times  
[2F] I get impatient sometimes  
[12F] It's kind of off-putting – I haven't the same patience with him  
[15F] I get frustrated  
[25M] I've got to be very patient  
[19F] My biggest problem is being sleepy headed  
[16F] There have been times when I've been very very tired

### **Dependency**

[3F] He was a loner, now he's more clingy  
[4F] He's got a little more possessive  
[6F] He's fearful, he was never fearful before  
[9F] I'm having to mother him  
[13F] He went a bit withdrawn  
[14F] He was dominant, now I'm dominant.  
[15F] I don't molly coddle him – I tell him for his own sake  
[18F] He's depending on me, I'd rather have that than have him further away. I'd rather he needed me than I needed him. I'm more of a mother figure than a wife

### **No Real Change / Adjusting / Resigned**

[1F] I've had a good life I can't complain  
[14F] We've done a lot and we don't have a dull life  
[13F] I think people find us about the same. You accept it, I don't expect to be gadding about all over the place anymore  
[2F] he's learning what he can do, sometimes he tries too hard  
[8F] Physically I'm worn out, mentally I'm adapting myself  
[10F] He's never been jolly and he's still not. You make adaptations where possible  
[16F] We've done quite well together – we do the best we can  
[23M] It's just the physical change in her – nothing else  
[27M] She's immobile – that's all  
[30M] It's all just the same – once you get to our age .. I'm content – what else could I want?

### **Lost Goals and Activities**

[1F] I'm less out and about now  
[6F] Life is centred round his illness. We've no got any life now  
[7F] It's interrupted our plans  
[8F] I'm accepting that I will have to give up things  
[10F] Well what is there left?  
[11F] We have less holidays  
[12F] I used to go out with the girls



[13F] We've had to shelve some things  
[21M] We used to be able to walk out together, and I get much less social time  
[30M] We can't get out the same – she's frightened  
[11F] He has so few friends now

### **Taking on New Roles**

[3F] I take more decisions, manage more things  
[5F] I try not take on his roles, but he looks to me to do everything, he used to look after me  
[14F] I've taken on more roles, like the finances. I've become stronger, I see my own personality again, learning new things – that's a plus. It's given me strength  
[15F] I can't talk things round with anyone anymore – I make the decisions on my own  
[26M] I do things I didn't do before  
[30M] We live our lives much the same as ever but I just do more of the work

### **Demands**

[2F] he's more impatient, complains more, but he's still rearing to go  
[4F] He continuously talks about his own ailments  
[5F] He's a bit dramatic, he gets me to do things for him he could maybe do  
[6F] He used to be very dominant, not now but he's demanding, selfish and abrupt  
[10F] He's sometimes a bit selfish, like I shouldn't be ill  
[12F] He's lazier, more easily upset, more vulnerable and more dogmatic  
[15F] He's not got much thought for anyone else – he's interested in himself and that's it  
[24M] She's an unusual personality, always looking for others to do things for her  
[17F] He doesn't demand, I can sit down when I want

### **Change in Intimacy**

[1F] There's less love now, more respect  
[2F] we always did things together  
[5F] The closeness has gone  
[6F] I feel it's made me harder, I've no got any feelings now. We still love each other, but the way we talk to each other now – it's awful (tears)  
[7F] It's mebbe made us a wee bit closer. I feel so sorry for him  
[8F] he's more considerate, not wanting to be a burden. I think I'm being a bit more considerate too.  
[9F] Sex-wise he's no able, he wants to and we cuddle and all the rest but he gets nothing out of it  
[10F] Love's flown out of the window. As you get older you see more faults, you're more in each other's company  
[12F] We've never been ... the children came first  
[14F] He's more amiable  
[14F] There's been a shift – we're both individuals in our marriage  
[16F] He's still the man I married  
[17F] There's no change really. We've slept separately for years.

[18F] We're more close, better at giving each other space. More like a brother and sister, more comfortable.  
 [20F] We dinnae bother about each other now. I just look after him.  
 [22M] There's less of a physical relationship now, but that's not a problem  
 [23M] We've always been very compatible  
 [24M] We've been estranged since the 1970's. She used to be colourful, now it's a nastier kind of thing. If I'd known then what I know now, I'd never have married her  
 [25M] One's really got to make up one's mind it shouldn't affect one's marriage  
 [26M] We maybe don't argue quite so much and she's maybe a bit more jovial  
 [27M] There's only one thing wrong and that's the physical side – we lost it a long time ago – it was my fault and I couldn't tell her (tears)  
 [29M] She'll not tell me anything, I feel left out.

## **FUTURE**

### **Living one Day at a Time**

[1F] I live one day at a time, always on the bright side  
 [2F] I just wait and see  
 [5F] I'm pretty philosophical about it. Cross bridges when they come  
 [7F] I live from day to day  
 [11F] I don't think about the future, just live from day to day  
 [12F] I just live from day to day.  
 [14F] I take it a day at a time, I can't go on worrying so I don't think about it as much as I used to  
 [29M] I don't think about it – you argue one day and then it's gone

### **Looking Ahead**

[4F] If we could just get him to think positively  
 [5F] I always look to the future, booking holidays, looking ahead  
 [15F] If we went to Glasgow there would be less need for me to look after him all the time and I could get out more  
 [16F] A fair amount of hope too, I think we could manage a holiday next year.  
 [23M] I feel alright about it. I'm still healthy  
 [26M] I like to be optimistic, I don't notice any great difference but they say there has been continuous and on-going progress  
 [26M] She may walk with a zimmer – that would be a big help  
 [27M] I realise we can't stay in the same house much longer, my son is building us a Granny flat. We've left it too late and now the physical problems make it so much harder  
 [28M] We've been looking around for a smaller house  
 [29M] I'm booked up again for a holiday, but whether she can go or no ...

### **Pessimism**

[2F] I feel it could happen again tomorrow  
 [3F] I don't think he'll last very long, he says he's done

[4F] I'm not very optimistic

[6F] I feel I've not got any future now – I like to see my family getting on. I can only see him getting worse

[7F] I'm not optimistic at all, I know things will get worse

[8F] Not terribly optimistic

[9F] I keep trying to be optimistic, but it's hard to visualise – the way he is at the moment

[10F] I feel life's going by too quickly and what is there to it now? I'm tied to the house

[13F] I've not got much confidence since he had his collapse, what was it??

[16F] I have a certain degree of fear about the future.

[21M] It's getting worse, for everybody

[25M] It's pretty dreadful.... Grim

[30M] I don't know, a holiday would be nice but we can't go as she is

### **Thoughts about Homes**

[3F] I don't mind doing it – I don't like the attitude of throwing your people in somewhere

[7F] I don't really want to think about it – going into a home – will it happen?

[8F] I'd rather have him at home because he likes being here

[10F] I would feel guilty if I put him in a home

[17F] I'm going to find out about homes

[25M] I'd hate the thought of putting her in a home.

### **Who will Live Longest**

[7F] He'll probably outlive me but he's not going to get better

[12F] I can't see us living so very much longer – which of us will go first?

[16F] I hope I outlive him, he couldn't live independently.

[22M] I suppose I'll be left alone eventually

[28M] What would happen if I kicked the bucket – it's on me mind – what help would be available?

### **Needing a Break**

[9F] Sometimes I wish I was on my own, not wishing him to die, but just a wee break

[10F] I must try and get a break, I feel I must – the winter's so long

## **DAY HOSPITAL**

### **Good for Partner – social, other suffering, physical**

[1F] It'll be good for him to be out. It might be the making of him, if not at least the hospital has tried

[5F] He enjoys getting out

[7F] it gets him out and speaking

[19F] I hope it might be good for him, seeing more people

[25M] .. she sees other people

[27M] It's bringing her out a bit

[28M] I'm for it – every little helps, it'll give her more confidence

[6F] It'll make him get about more and see other people that's ill  
[13F] he can get out and see other suffering more than him  
[18F] It's nice to see him going out to see people, and people worse off than him  
[12F] I'll be quite glad if he goes, they might get him walking about

### **Good for Self – a break, others take responsibility**

[2F] I feel it's quite good – it gives me a break and he's less stressed  
[5F] It gives me a break  
[6F] I think it's good – a relief  
[7F] I'm glad because it gives me a break.  
[8F] It's great – they'll monitor him and it gives me a day off - I might go out and treat myself  
[9F] I can always get bits of things done that I can't do when he's here  
[10F] It'll give me a morning to myself  
[12F] ... I'll be able to go out  
[13F] It's lifted a load off my mind  
[15F] I can get out and about  
[18F] I go out for the day, shopping  
[19F] I could meet up with my sister again  
[20F] It'll give me a wee break  
[21M] This sounds OK, as long as it's medical. It gives me a break  
[23M] Quite pleased about it. I can go and have a game of golf  
[24M] I won't have to be in at lunchtime to feed her.  
[25M] I get some extra time, play golf  
[26M] I'm more free to do my own thing  
[27M] I can now disappear – a chance to sneak off  
[29M] It leaves me free to go to the bowls  
[11F] It gives me some respite and he gets properly assessed  
[14F] It's quite a relief. If there is anything it would be picked up. .. It gives me time for myself  
[22M] Other will have the responsibility if something goes wrong

### **Will they Go?**

[3F] I'm pleased, I want him to attend but I can't depend on him going  
[7F] He would be happy not to go  
[10F] I'm happy about it. He's not so happy, but he's going!  
[12F] He doesn't want to go and I'll not force him  
[13F] I think it's great, but he doesn't want to go – 'geriatric'  
[24M] The DH will be great, splendid, as long as she doesn't play up with them.  
[26M] She was apprehensive about it

### **Not needed**

[4F] It's not really needed – we just wanted a referral to psychology  
[15F] If he comes out the way he did last time he was no different.  
[16F] I don't think there's anything they can do to help and I don't feel I need a rest  
[21M] She used to go to a day hospital for depression – it came between us, could've been a bust up

[25M] I think it's a racket. All they do is sit about. They try, but do they succeed?

[27M] She's been supposed to come several times, but it never happened

[30M] She won't like it, what can they do? She likes to be in the house

## **COPING**

### **Confrontation**

[1F] I don't let him away with everything

[4F] Sometimes I just tell him to stop

[9F] I shout at him and then he realises

[10F] I lose the head, shout and bawl. He can't hear me, he's deaf.

[12F] Perhaps I am unreasonable – I say to him I'm going out, but he doesn't like it

[27M] We never fight – just skirmishes

### **Relaxation**

#### **Escape**

#### **Distraction**

[5F] Take deep breaths, go out into the garden, listen to music

[26M] I'm quite glad just to sit down sometimes

[6F] I go into a room and shut the door, or I get out of the house.

[8F] If I feel I can go out, I go for a walk

[13F] I just get out for a while

[14F] I go out or phone someone till I calm down

[20F] I come into the spare room and do things

[3F] I watch TV, or the radio

[12F] I sit and bury myself in my books

[16F] I try and find something to do that's got nothing to do with it all – a wee spell that's all for me

[28M] I maybe do a wee bit of gardening or clean the car

### **Self Talk**

[7F] I talk myself out of it, I try to hide the tears

[13F] You have to say 'Well some of the fun was taken out of his life', and keep cheerful

[21M] I just put it out of my mind, think of something else

### **'Getting On'**

[3F] Why moan – he never moans

[15F] It's like a job, you've just got to get through the things you have to do

[16F] I've always been good at making the best

[23M] I've always been an easy going sort of person

[25M] One's just got to get on with it. It's a terrific strain, unending

[29M] It's not at all stressful

[30M] I've no got so much to do, she's no too bad

### **Miscellaneous**

[6F] And I'm drinking more.

[9F] I have a good cry  
[17F] I sit and greet  
[23M] I try to make a joke about it, rather than losing it  
[26M] I like to get up and ready first – there's an order to things  
[11F] Outsiders see it more, my daughter sometimes says 'Mum you need a rest'  
[14F] If he was difficult it would be a different matter, but he's more amiable  
[27M] I couldn't cope with her being senile

## **BEING A CAREGIVER**

### **Commitment, Duty, Vows, Brought up to it**

[1F] It's a commitment to him, he deserves to stay at home  
[5F] It's all part of the relationship. You have to take the good times with the bad times. It isn't a cross to bear, it's just a part of our life  
[6F] I was brought up to help and to look after your own.  
[7F] 'For better, for worse'. I'm in a marriage, I would never do it for someone else  
[10F] It's kind of my duty  
[11F] It's a duty, part of the marriage  
[12F] We were brought up to it, no matter how bad things are you never walk out, I believe in the marriage vows  
[14F] I'm just a housewife, not a caregiver  
[16F] I see it as a contract I entered when we married, the vows. I'm a wife.  
[21M] You take vows, you gotta live with them. But there's no enjoyment  
[23M] You feel it's your duty, it's how you should do it. I'd help you!  
[24M] It's part of the game, you take something on and you see it through. I took her on, there's no use gurning about it. 'In sickness and in health', it's my duty. I wouldn't like myself if I wrote her off – I'm doing it for me.  
[28M] It's a part of marriage,, when I took me vows it was for better or worse. Not like these youngsters

### **It's Just Helping Out**

[2F] I'm not paying back, I'm doing what's required  
[4F] I'm just giving a helping hand  
[7F] I have to do it, I want to help him.  
[9F] I feel I can't do enough to help him – it's frustrating

### **Pleasurable? Rewarding?**

[3F] I feel he appreciates it  
[8F] Yes, I am a caregiver. It doesn't much appeal to me.  
[18F] I need it hen, it's what I'm needing. This is how I like it. I'm doing it for pleasure, not for duty. It's the happiest time of my life.  
[22M] I've been looked after well, now it's my turn  
[26M] I'm glad I'm able to do it. If I hadn't been as fit it wouldn't have been possible  
[27M] I wouldn't want to do anything else – no regrets  
[29M] I do the best I can for her  
[30M] It keeps you fit – keeps you're weight down!